

**The Health Care Challenge:
Acknowledging Disparity,
Confronting Discrimination,
and Ensuring Equality**

**Volume II
The Role of
Federal Civil Rights
Enforcement
Efforts**

A Report of the United States
Commission on Civil Rights
September 1999

U.S. Commission on Civil Rights

The U.S. Commission on Civil Rights is an independent, bipartisan agency first established by Congress in 1957 and reestablished in 1983. It is directed to:

- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, disability, or national origin, or by reason of fraudulent practices;
- Study and collect information relating to discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice;
- Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice;
- Serve as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, disability, or national origin;
- Submit reports, findings, and recommendations to the President and Congress;
- Issue public service announcements to discourage discrimination or denial of equal protection of the laws.

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Letter of Transmittal

The President
The President of the Senate
The Speaker of the House of Representatives

Sirs:

Pursuant to Public Law 103-419, the United States Commission on Civil Rights transmits this report, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*. With this two volume report, the Commission examines the efforts of the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) in enforcing title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, the requirements under the Hill-Burton Act of 1946, and the nondiscrimination provisions of the community block grant programs administered by HHS. In particular, the Commission's report focuses on the enforcement of these nondiscrimination laws and their impact on ensuring equal access to quality health care for all Americans, particularly women and people of color.

Volume II of this report, *The Role of Federal Civil Rights Enforcement Efforts*, highlights significant weaknesses in the Office for Civil Rights' enforcement efforts. The deficiencies largely are the consequences of OCR's fundamental failure to recognize the tremendous importance of its mission and to embrace fully the opportunity it has to eliminate disparities and discrimination in the health care system. While OCR has attempted over the years to identify noncompliance with the Nation's civil rights laws, its efforts have been merely reactive and insufficient to remedy the pervasive problems that exist within the system. As a result of its myopic perspective, OCR is unable to plan systematically and implement the kind of officewide redevelopment policy that it so clearly needs. OCR's failure to appreciate its role is part of a larger impotence that afflicts the entire agency's approach to civil rights: the Department has failed to assert its civil rights enforcement authority with regard to the health care system.

Because OCR has a relatively small budget compared with other HHS agencies, OCR staff must search for creative solutions to fiscal challenges. OCR has been especially reluctant to assume an active role in seeking innovative alternatives. In many ways, OCR has neglected to take advantage of opportunities to bolster its own enforcement efforts by cooperating with other agencies within HHS, as well as outside the Department.

Another important aspect in which OCR has fallen short of its civil rights mandate is the dissemination of regulations and policy guidance, a critical function of civil rights implementation programs. Unfortunately, OCR has issued virtually no policy guidance on title VI, title IX, or the block grant nondiscrimination provisions since 1981. This lack of productivity is of particular concern with regard to title VI, because many new forms of discrimination against people of color have emerged as the Nation has moved from "fee-for-service" medicine to managed care. Without appropriate policy guidance, neither recipients or beneficiaries of Federal funding, nor OCR investigative staff, can develop a clear understanding of what constitutes discrimination by managed care and other health care organizations.

Further, OCR appears to have largely abdicated its role in the compliance enforcement process. OCR headquarters has failed to provide leadership to the regional offices, from assisting them in setting priorities, to offering procedural guidance for investigations. This failure has hindered the regional offices' abilities to identify and eradicate discrimination. Perhaps the most serious shortcoming in OCR headquarters' leadership is that it has neglected to acknowledge and confront systemic discrimination. Although studies suggest that the health care industry is replete with large-scale discrimination, OCR has devoted minimal resources to identifying pattern and practice discrimination therein.

The new director of the Office for Civil Rights has indicated his commitment to ensure quality health care for all Americans and to eliminate discrimination and disparities in health care services. To assist with this effort, the Commission has the following recommendations for Congress and the President. First, Congress should recognize the fundamental importance of health to our Nation, and should in its next session pass legislation proclaiming equal access to quality health care as a universal right of all who reside within the Nation's borders. An integral component of this statute would involve data collection: Congress should direct the agency charged with implementing this statute to collect and analyze health care data sufficient to comprehensively assess all disparities in health care, and should prescribe a detailed data collection plan for the agency to follow.

Second, Congress should immediately conduct an oversight hearing on civil rights enforcement within HHS-assisted programs, assessing both OCR operations and the Secretary's coordination of civil rights implementation. Third, Congress should provide OCR with the necessary resources to carry out all of its responsibilities effectively and efficiently: OCR's resources are manifestly disproportionate to the wide array of Federal assistance programs the agency administers, accounting for only .0054 percent of the entire HHS budget for fiscal year 1999. Fourth, Congress should convene an HHS civil rights task force that will periodically reevaluate the agency's operations until it is satisfied that OCR has implemented the changes recommended by the Commission and outside organizations. As part of this effort, HHS/OCR should be required to devise a civil rights improvement plan and report annually on its efforts to accomplish the objectives outlined therein.

Fifth, the President should issue an Executive order delineating and reaffirming HHS' civil rights enforcement mandate, emphasizing that HHS has been delegated *all* authority necessary to identify and eradicate discrimination in health care. Finally, the Commission also calls for the President and the Secretary of the Department of Health and Human Services to issue a joint statement strongly reinforcing their commitment to the enforcement of civil rights statutes in the health care context.

Equal access to quality health care for all Americans can be achieved during the early part of the new century. However, to achieve this goal there must be vigorous enforcement of existing nondiscrimination laws. With a renewed national commitment to improve the health status for all citizens and to eliminate discrimination and disparities in health care, this goal will be a reality.

Respectfully,
For the Commissioners,



Mary Frances Berry
Chairperson

Preface

Introduction

Equal access to quality health care is a crucial issue facing our Nation today. For too long, too many Americans have been denied equal access to quality health care on the basis of race, ethnicity, and gender. Cultural incompetence of health care providers, socioeconomic inequities, disparate impact of facially neutral practices and policies, misunderstanding of civil rights laws, and intentional discrimination contribute to disparities in health status, access to health care services, participation in health research, and receipt of health care financing. Such disparities persist in part because of inadequate enforcement of Federal civil rights laws relating to health care by the U.S. Department of Health and Human Services (HHS). For many years, title VI of the Civil Rights Act of 1964, the community service assurance provisions of the Hill-Burton Act, title IX of the Education Amendments of 1972, and the nondiscrimination provisions of block grant statutes have not been fully enforced and implemented by HHS' Office for Civil Rights (OCR).

Equal access to quality health care is a civil right. Although Congress has enacted civil rights laws designed to address specific rights, such as equal opportunity in employment, education, and housing, it has not given health care the same status. Regardless, unequal access to health care is a nationwide problem that primarily affects women and people of color. The lack of availability and quality of health care, the lack of affordable financing of health care, and the likelihood of minorities and women not being included appropriately in medical research are realities as we approach the 21st century. Despite the many initiatives and programs implemented at the Federal, State, and local levels, the disparities in health care will not be alleviated unless civil rights concerns are integrated into these initiatives and programs.

The Commission's Evaluation of Civil Rights Enforcement at HHS

The Commission's two reports on equal access to health care as a civil right develop complementary themes, with volume I setting the stage for volume II. With these reports, the Commission provides recommendations focusing on eliminating racial, ethnic, and gender disparities in health care and improving HHS' civil rights enforcement activities. These reports clearly demonstrate that OCR has been operating in a vacuum for many years, has not asserted its enforcement authority, and is not necessarily aware of the many initiatives and programs aimed at improving access to health care for women and minorities. Volume I documents the need for more collaboration between OCR and Federal, State, and local agencies; the deficiencies and disparities highlighted in volume I can be significantly reduced through proper civil rights enforcement, as identified in volume II.

This report is the result of months of research and careful assessment of materials gathered from a wide variety of sources. In an effort to conduct balanced research, Commission staff solicited diverse scientific viewpoints by contacting numerous private research and advocacy organizations, including organizations representing alternative viewpoints. Further, in gathering information, a request was sent to more than 150 health care organizations, professional groups, research institutes, and advocacy groups representing a wide range of constituents and from all points on the political spectrum. In addition, medical schools, teaching hospitals, and State health agencies across the country were contacted for input.

Statements in these reports are based on interviews, HHS documents, and research findings. The pertinent health care issues presented have been identified by the Federal Government as well as private health care organizations and researchers. The discussions in both volumes of the report were informed by multiple sources, as is evidenced by the bibliography which includes more than 350 documents, articles, and interviews. Included are HHS docu-

ments, studies and surveys by national organizations, articles in health care research journals, and other research that cites experts in the field.

As the law must comprise the foundation for any enforcement evaluation, the Commission consulted law review articles, as well as statutes, regulations, guidelines, and policy guidance. In addition, to encompass the medical aspects of the issue, the report includes the viewpoints of numerous physicians and medical experts (researchers and practicing physicians) by way of the medical journals, government and private reports, and law review articles. Data cited are from reputable sources such as the American Medical Association, the Association of American Medical Colleges, the National Institutes of Health, the National Center for Health Statistics, and other agencies in the Department of Health and Human Services. The stories told by the majority of these sources reveal the findings presented in this report: that health care disparities continue to exist, and proactive, effectual remedies are imperative.

Health Disparities

Barriers to Access to Health Care

In developing this report, it was discovered that there is no universal agreement on the causes of racial, ethnic, and gender disparities in health status, nor is there only one source of such disparities, but there are a few that have the most direct effect. One obvious determinant of health status is access to health care, including preventive care and necessary treatment. Factors that impede access to care are discussed in detail throughout this report. For example, health care financing, particularly the ability to obtain health insurance, is one of the most prevalent health care concerns of all Americans and presents a particular challenge for minorities and women.¹ Other barriers to access identified in this report include language barriers, cultural misunderstanding on the part of both the provider and the patient, lack of available services in some geographical areas (such as inner cities and rural communities), and lack of transportation to services.

Behavioral Factors and Health

Critics will often cite lifestyle and behavioral habits as defining factors of health status; however, this is a faulty assumption in many instances. While it is true that certain lifestyle behaviors—smoking, alcohol consumption, poor diet, etc.—can be correlated to poor health status, this report demonstrates that these behaviors actually account for only a modest portion of health disparities across age, sex, and race categories.² This argument also fails to take into consideration the extent to which personal choice is limited by opportunities, such as low income, the unavailability of nutritious foods, and lack of knowledge about healthy behaviors. When personal responsibility is cited as the sole explanation for poor health, factors that are not entirely within an individual's control can become a source of blame. This is not to suggest that individuals should not take responsibility for their own health, rather it is acknowledged that personal responsibility should become part of the regimen for improving health.³

Socioeconomic Status and Poor Health

A major premise of volume I of this report is that the combined variables of race, ethnicity, gender, and socioeconomic status intersect to have an undeniable adverse effect on the ability of many Americans to obtain health care. Certainly, health status is related to poverty; and socioeconomic status and race are intimately linked.⁴ As the findings here indicate, overall, minorities have a lower median weekly income and are more likely to be below the poverty line than

¹ See vol. I, chap. 3.

² See vol. I, chap. 2.

³ See vol. I, chap. 2.

⁴ See vol. I, chap. 2.

whites.⁵ Inequalities in education, income, and occupation account for some, but not all, of the race- and gender-related differences in health status, access to health care, health research, and health care financing. For example, persons with lower income are more likely to report being in fair or poor health. Similarly, the association between poverty and health status can be seen within racial and ethnic groups, but racial and ethnic disparities remain even within income groups.⁶ Thus, income does not explain all the racial and ethnic disparities in health status.

Volume I also addresses how poverty affects the ability to obtain health insurance coverage.⁷ Again, it was shown that income level has a large effect on the number of individuals who are uninsured or privately insured. However, as this report confirms, race and ethnicity compound the effects of poverty, as demonstrated by differences in insurance rates. Disparities in insurance coverage vary markedly by race and ethnicity beyond the effects of income on that coverage.

Many studies have shown that even when income and other factors (such as age, severity of disease, and health insurance coverage) are taken into account, there are still statistically significant racial differences in health status, treatments received, and other measures of access to health care.⁸ Further, other measures of disparity, such as waiting times, should not be affected by gender, race, or ethnicity; yet disparities are found between population groups. Thus, major racial, ethnic, and gender disparities remain in health status and access to health care even after socioeconomic factors are taken into account. These remaining disparities give rise to concerns that discrimination and bias exist in our health care system.

Discrimination and Disparate Impact

The evidence of discrimination by health care providers and insurers is overwhelming. Each volume of this report presents numerous instances where individuals have been either treated differently or denied treatment due to race, national origin, or gender. For example, volume I presents evidence which shows that certain procedures are less frequently prescribed for minorities. Whether this disparate treatment arises directly from the fact that they are minorities or because of other factors which disproportionately affect minorities is a matter of splitting hairs. The effect is the same: discrimination.

This report, particularly in volume II, demonstrates that disparities in health status and access to quality health care may be the result of the disparate impact that certain policies or procedures have on women and members of racial/ethnic groups. Critics of disparate impact theory of discrimination have contended that it is not a valid basis for discrimination charges or complaints. These critics often assume that, in the context of allegations of discrimination relating to a health care provider or insurer, if intentional discrimination is not involved, no legal issue exists. However, the Supreme Court has held that disparate impact is a form of discrimination, prohibited by the implementing regulations of title VI of the Civil Rights Act of 1964 and by

⁵ In 1997, for example, 8.6 percent of white families lived below the poverty line, compared with 26.5 percent of black families, 27.1 percent of Hispanic families, and 14.0 percent of Asian American and Pacific Islander families. U.S. Department of Commerce, Bureau of the Census, "Poverty 1997," accessed at <<http://www.census.gov/hhes/poverty/poverty97/pv97est1.html>>. In 1998 the median weekly earnings for white men was \$615, compared with \$468 for white women and black men, \$400 for black women, \$390 for Hispanic men, and \$337 for Hispanic women. U.S. Department of Labor, Bureau of Labor Statistics, *Employment and Earnings*, January 1999, table 37, accessed at <<http://stats.bls.gov/cpsaatab.htm>>.

⁶ See vol. I, figure 2.2.

⁷ See vol. I, chap. 2.

⁸ American Medical Association, Council on Ethical and Judicial Affairs, "Black-White Disparities in Health Care," *Journal of the American Medical Association*, vol. 263, no. 17 (May 2, 1990), pp. 2344–46. See, e.g., G. Caleb Alexander and Ashwini R. Sehgal, "Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor," *Journal of the American Medical Association*, vol. 280, no. 13 (Oct. 7, 1998), pp. 1148–52 (finding that after adjusting for income, sex, age, cause of renal failure, and years on dialysis, blacks and women were less likely than white men to receive transplants).

title IX of the Education Amendments of 1972.⁹ Congress further recognized disparate impact as an appropriate theory of discrimination in the Civil Rights Act of 1991.

The Importance of Physician Diversity and Cultural Competence

Research suggests that minority physicians and dentists are more likely to serve minority patients and communities where a shortage of health care providers exists, and are more likely to provide services at reduced fees. In addition, studies have found that physicians of the same race and/or sex of the patient may be more effective than physicians with different backgrounds from their patients. A recent report in the *Journal of the American Medical Association* stated that both black and white patients feel more involved in their health care when their physicians are of the same race.¹⁰ The result is higher patient satisfaction, increased likelihood that the patient will follow through on treatment, and ultimately better medical care. According to the researchers who conducted the study, these findings suggest that doctors need better training to improve cross-cultural communication.

Cultural barriers in the form of misunderstood customs, the inability to express one's health needs, and lack of trust in the health care system are factors that might hinder a physician's ability to provide adequate treatment to his or her patients. Thus, what this report finds is that, within the context of patient care, it is necessary to open up medical knowledge to include multicultural perspectives to health, health care, and patient-provider interaction. This view does not assume that race is a major determinant of how patients select their doctors or that doctors cannot communicate with people of other cultures. The reason for cultural competency training for health care professionals is to enhance the quality of health care delivery. Cultural competency training is essentially a measure to help medical professionals gain more knowledge about their patients. Further, this report calls for a mandate that health care information be translated into languages for beneficiaries who have difficulty communicating in English, enabling patients to comprehend and participate in the decisions related to health care.

A major finding of the research conducted here is that clearly more minorities are needed as health care professionals. This report supports affirmative action programs that increase the opportunities for minorities in the health professions while maintaining high standards and qualifications for physicians and other health care professionals. For example, the findings in this report suggest that HHS and the Department of Education must support efforts to raise minority students' interest in pursuing medical professions, to increase the academic qualifications of minority students so that they can pursue medical study, and to promote the valuing of diversity within the medical profession.¹¹

Affirmative action must be construed more broadly than through the admissions standards for acceptance into medical schools. For instance, initiatives to improve educational opportunities, particularly in math and science, at the elementary, secondary, and postsecondary levels will better prepare all students to pursue medical studies. In conjunction with these initiatives, some of which are illustrated through innovative examples in this report, recruitment efforts can potentially increase the pool of qualified medical school applicants. Thus, rather than suggesting that affirmative action efforts have failed or that admission standards should be lowered, this report indicates that affirmative action efforts should be broadened to include other initiatives.

Volume II of this report highlights the important role the Department of Health and Human Services' Office for Civil Rights must play in promoting initiatives to increase the number of minority physicians. OCR has numerous mechanisms to address issues relating to its civil

⁹ See *Guardians Assoc. v. Civil Service Comm.*, 463 U.S. 582 (1983).

¹⁰ Lisa Cooper-Patrick, Joseph J. Gallo, Junius J. Gonzales, Hong Thi Vu, Neil R. Powe, Christine Nelson, and Daniel E. Ford, "Race, Gender, and Partnership in the Patient-Physician Relationship," *Journal of the American Medical Association*, vol. 282 (Aug. 11, 1999), pp. 583-89.

¹¹ See vol. I, chap. 2.

rights enforcement mission. For example, with regard to affirmative action, the report recommends that OCR develop policy guidance to clarify what universities may and may not do under existing law to increase student, faculty, and curricular diversity.¹² In addition, OCR can provide technical assistance and outreach and education to medical schools to assist them in increasing the pool of qualified applicants through extensive recruitment efforts. The fact that numerous universities actively engage in diversity-enhancement programs in itself demonstrates the need for OCR to disseminate guidance on educational institutions' legal responsibilities in this important area.

In addition, the report finds that it is important to encourage girls and women to pursue careers in medicine. Data from the American Medical Association cited in volume I indicate that in 1995 nearly 60 percent of the women practicing medicine were clustered in five areas: internal medicine, pediatrics, family practice, obstetrics/gynecology, and psychiatry.¹³ Additional evidence indicates that women face difficulty breaking into medical research careers, further limiting the "choices" available to them. The fact that women physicians are clustered into a few areas of specialties presents a curious phenomenon. While it is true that there is some degree of choice involved in the election of medical specialty, the extent to which women "choose" certain areas is unclear.

Researchers have found subtle signs that many women are discouraged from entering new high-tech medical fields, and there is evidence that women medical students are steered into more "accepted" specialties. For example, one study cited in the report found that of female medical students surveyed, only 8 percent had originally named pediatrics as their chosen specialty, but one-third eventually entered pediatric residencies.¹⁴ This suggests that some occurrence during the course of medical training steered these women toward a field that was not originally intended. The consistent low number of women in certain specialties, including new high-tech medical fields, raises the concern that if this trend continues, the medical profession may become gender identifiable, whereby women are centered in the areas of family medicine and primary care, and men are more concentrated in the new specialized medicines or surgical subspecialties.

Evidence presented here also indicates that women researchers receive a disproportionately smaller share of research funds, compared with their male counterparts. Overall, the report recommends that HHS ensure that funds are awarded in a nondiscriminatory manner. Funding should be based on merit, and both male and female researchers should be provided an equal opportunity to apply for and receive funding. The fact that fewer women apply for grants is one part of the problem which needs to be addressed.

Inclusive Research

Research indicates that minorities and women—particularly minority and poor women—have been excluded from clinical trials for decades. However, this exclusion is not attributed in all cases to discrimination or intentional omission. In some instances, women and minorities have been excluded from trials because the illness under study was thought to be more relevant to men or to certain subpopulations. These medical assumptions (which have sometimes proven erroneous) must be reassessed and based on scientific fact, which cannot be determined unless all populations are studied.

Many women of color, in particular, do not participate in research studies not because of discrimination per se, but because many of them are not informed of such studies or are unaware of the importance of participating in such studies. While the demographic makeup of a community being studied will usually dictate the sample of participants, those residents need to have information about such research. This report strongly urges implementation of Federal, State,

¹² See vol. II, chap. 7.

¹³ See vol. I, chap. 2.

¹⁴ See vol. I, chap. 2.

and local education and outreach activities that emphasize the importance of medical research. It does not necessarily advocate special research projects for women and minorities, but rather focuses on strategies to include them in medical research, so that medical findings are applicable to all populations.

The scientific research community acknowledges that women and minorities have been excluded from research, and in recent years emphasis has been placed on the medical necessity of inclusion. As a result, the major research divisions at HHS (National Institutes of Health, Food and Drug Administration, and Centers for Disease Control) have all passed guidelines mandating the inclusion of women in clinical trials.¹⁵ The fact that the issue of including women and minorities in research has become a major political and scientific concern is further proof that there is indeed a problem, and a solution is necessary. In addition to studying female-specific health issues, it is necessary to examine how "gender-neutral" conditions are experienced differently by women and men. If women are not included, the data gathered do nothing to advance the knowledge of those diseases in women.

Conclusion

The recommendations offered by the Commission in this report are largely based on one foundation: the moral belief that, like education, housing, and employment, health care is a fundamental element of the human experience, and should be pursued by all on equal ground. The disparities documented by this report, however, indicate that existing laws have not succeeded in realizing this goal. One critical reason for ineffective enforcement of existing law has been the lack of commitment to equal access to quality health care as a civil right. That is why this report upholds the necessity of a statute that explicitly recognizes health care as occupying the same position of social importance as education, housing, and employment, and that creates an agency to ensure that health care maintains that stature.

In addressing disparities and subtle forms of discrimination infecting our health care system and adversely affecting health care access and outcomes for minorities and women, we as a nation have two options. The first option is to do nothing. Under this plan not a single Federal dollar is spent to conduct civil rights enforcement efforts or to support programs and initiatives designed to reduce these disparities. This option requires the Nation to conceptualize the disparities in our health care system in one of three ways. The first is to simply accept that there have always been disparities in access to employment, education, and even health care, and to ask the question, "Why change now?" The second is to manipulate statistics to show that such disparities do not really exist; so again, we may tell ourselves that no change is needed. Finally, those who actually have access to quality health care can insist that "personal responsibility" and the sense to make "good choices" are the solutions to all of our societal ills. These sentiments justify the abdication of our responsibility as a nation to eradicate discrimination and disparities in the health care system.

The second option is to take action. This option requires that we recognize health as the foundation of our well-being as individuals and our productivity as a nation. To do this we must first develop a national vision for the elimination of disparities in access to *quality* health care, and the subsequent reconciliation of health status between minorities and non-minorities and women and men. This option requires a collaboration between Federal, State, and local governments, as well as private organizations to: (1) raise public awareness of health care as a fundamental component of the Nation's agenda, (2) acknowledge community-specific needs to ensure that all individuals have the opportunity to participate in their own health care, (3) implement initiatives designed to promote access to health care for the underserved, and (4) foster vigorous enforcement of civil rights as the vehicle by which equality in health care is ultimately achieved.

¹⁵ See vol. I, chap. 3.

Acknowledgments

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*Former Commission employee

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Chapter 1

Introduction

Federal Civil Rights Enforcement in Health Care: A Historical Perspective

1963: "Racial discrimination, resulting in the denials of equal protection of the laws, plays a significant role in the area of health facilities and services. . . . Racially discriminatory policies and practices are found in every region of the Nation."¹

1998: "A divided health system persists, both exacerbating and distorting racial disparities. In spite of the federal efforts to end segregation, health care remains, at best, more than half the distance between a fully separate and an integrated system. The Northeast and Midwest rather than the South now provide the most racially segregated health care. Nursing-home care tends to be the most segregated, and ambulatory care remains highly segregated as well."²

The Commission has been monitoring civil rights issues related to quality health care for several decades. Although there have been substantial improvements in access to quality health care since the 1960s, several of the Commission's recommendations to Federal agencies, such as the U.S. Department of Health and Human Services, have gone unheeded. An examination of the history of discrimination in health care and efforts to eliminate such discrimination reveals that many aspects of discrimination are rooted in historical practices.³

¹ U.S. Commission on Civil Rights (USCCR), *Civil Rights '63: 1963 Report of the United States Commission on Civil Rights*, p. 142 (hereafter cited as USCCR, *Civil Rights '63*).

² David Barton Smith, *Health Care Divided: Race and Healing a Nation* (Ann Arbor, MI: The University of Michigan Press, 1999), p. 319.

³ See David Barton Smith, "Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards," *Journal of Health Politics, Policy & Law*, vol. 23, no. 1 (February 1998), pp. 75–105.

Before 1964

Prior to the passage of the Civil Rights Act of 1964, health care facilities in both the southern and northern United States were segregated, as were medical schools and nursing programs. Black physicians were routinely denied admitting privileges to hospitals. In some hospitals, when the white section of the hospital was full, black patients were moved into the hallways to provide rooms for white patients.⁴ One scholar writing about this period has provided an example of hospital care for blacks in the 1950s and earlier:

During the first half of the century, black patients in Wilmington, North Carolina, were treated at one of two hospitals. James Walker Memorial Hospital maintained 25 beds for blacks, but in a separate building approximately 30 yards from the main hospital. To reach the operating rooms, the delivery room, or the x-ray department, patients were transported outside. The medical staff was restricted to white physicians. The other facility, Community Hospital, provided 96 beds for black patients. Although its medical staff was biracial, black physicians provided most of the patient care. In 1955 three black physicians, Hubert Eaton, Daniel Roane, and Samuel Gray, applied for courtesy privileges at Walker Hospital. Their applications were denied because of race.⁵

In 1946 Congress passed the Hospital Survey and Construction Act, known as the Hill-Burton Act,⁶ which established Federal funding for the construction and modernization of hospitals and other health care facilities. Their initial motivation in enacting the law was to address the problem of the deteriorating conditions of hospi-

⁴ See generally *ibid.*

⁵ Edward C. Halperin, M.D., "Desegregation of Hospitals and Medical Societies in North Carolina," *New England Journal of Medicine*, vol. 318 (Jan. 7, 1988), pp. 58–63 (citations omitted).

⁶ Pub. L. No. 79-725, 60 Stat. 1040 (1946) (codified as amended at 42 U.S.C. §§ 291–291o (1994)).

tals in rural areas. The act stated that each State "shall provide for adequate hospital facilities . . . without discrimination on account of race, creed, or color."⁷ Nonetheless, the same section of the Hill-Burton Act exempted racially segregated hospitals from this requirement, so long as they provided "facilities and services of like quality."⁸ Hence, discrimination in health care facilities was allowed to persist.

Seventeen years after the passage of the Hill-Burton Act, the Commission argued that the "separate-but-equal" provision of the Hill-Burton Act had resulted in racial disparities in access to health care.⁹ The report noted that of the four cities where it conducted field studies or hearings, only one had eliminated the problem of unequal access to health facilities by race.¹⁰ The Commission concluded, "To the extent that [discriminatory] policies and practices limit the provision of medical care to persons in need, the health of the Nation is adversely affected."¹¹ The exemption in the Hill-Burton Act for segregated facilities had been successfully challenged and overturned by the end of 1963,¹² and the Civil Rights Act of 1964 further clarified the prohibition of discrimination in federally funded programs.¹³

The 1960s: After Title VI

Congress enacted title VI as part of the sweeping civil rights legislation it passed in 1964. Title VI identified three protected classes (race, color, and national origin) and made it

unlawful to discriminate based on personal characteristics such as these in implementing any federally assisted program.¹⁴ Title VI provides that "[n]o person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."¹⁵ The objective of title VI is to prohibit recipients of Federal funds from discriminating against the intended recipients, participants, or beneficiaries of Federal monies. As applied to programs operated by HHS, title VI requires HHS to administer and enforce title VI through the issuance of rules, regulations, or orders establishing the standards for compliance.¹⁶ HHS rules, regulations, and orders must be "consistent with the achievement of the objectives" of the program or activity for which the financial assistance is being extended.¹⁷ Most importantly, title VI empowers HHS with the authority to conduct preaward reviews, compliance reviews, complaint investigations, conciliations, sanctions, mediations, and settlements, and to refuse funding to or terminate funding for any recipient found in violation of title VI regulations, after an opportunity for an administrative hearing and voluntary compliance.¹⁸

Nonetheless, Commission reports of the 1960s and 1970s reveal that implementation and enforcement of title VI was occurring very slowly, when it was occurring at all. In conducting field investigations at hospitals in the South, the Commission found that in 1965 several hos-

⁷ *Id.* § 622(f). This section, including the discriminatory language, was replaced with the current section, whose nondiscrimination provision simply states that the facility must "be made available to all persons residing in the territorial area." Pub. L. No. 88-443, sec. 3, § 603(e), 78 Stat. 447, 451 (1964) (codified at 42 U.S.C. 291c(e) (1994)). See also USCCR, *Civil Rights '63*, p. 130.

⁸ Pub. L. No. 79-725, § 622(f). The Commission's 1963 report referred to this language as a "separate-but-equal provision." USCCR, *Civil Rights '63*, p. 130.

⁹ USCCR, *Civil Rights '63*, p.130.

¹⁰ *Ibid.*, p. 135.

¹¹ *Ibid.*, p. 142.

¹² *Simkins v. Moses H. Cone Memorial Hosp.*, 323 F.2d 959, 969 (4th Cir. 1963) (en banc), cert. denied, 376 U.S. 938 (1964).

¹³ Pub. L. No. 88-352, title VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d-2000d-7 (1994)). See also USCCR, *Equal Opportunity in Hospitals and Health Facilities: Civil Rights Policies Under the Hill-Burton Program*, CCR special publication no. 2, March 1965, pp. 6-9.

¹⁴ 42 U.S.C. § 2000d (1994).

¹⁵ *Id.*

¹⁶ *Id.* at § 2000d-1 (1994). Title VI allows HHS to enforce compliance with its rules, regulations, or orders either: (1) by terminating or refusing to grant or to continue financial assistance, or (2) by "any other means authorized by law." *Id.* No action of any kind, however, may be taken unless and until HHS has advised the recipient of its failure to comply and has determined that compliance cannot be achieved voluntarily. If HHS selects termination or discontinuance of financial assistance as the means of enforcement, it may not terminate funds until and unless there has been an "express finding on the record, after opportunity for hearing," of noncompliance. Further, its action must be limited in its effect to the particular recipient, or part thereof, and the particular program in which a violation has been found. *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

pitals continued to have discriminatory practices. For example, some hospitals with more than one building and hospital systems operating in more than one location continued to segregate black and white patients.¹⁹ The Commission also found that while, in many instances, racially segregated floors had been eliminated, patients continued to be assigned to rooms based on race.²⁰ Overall, two-thirds of the hospitals included in the Commission's survey were not in compliance with title VI one year after its implementation.²¹ In a related report published in 1964, the New York State Advisory Committee to the Commission noted that there was "definite racial discrimination in the assignment of patients to rooms and beds."²² The advisory committee also found that although there was no evidence of discrimination in the local medical and nursing schools, "[s]ome suspicion of discriminatory admissions policy at the former University of Buffalo School of Dentistry was suggested by the statistic of one Negro graduate in approximately 40 years."²³

According to one scholar, the civil rights efforts undertaken in the 1960s to provide racial equality in access to health care dissipated after 1968.²⁴ There were several reasons for the lack of attention to discrimination in health care:

The larger environment was not conducive to addressing issues of racial equity. Most of the easy, visible gains in eliminating Jim Crow symbols had been achieved. The more difficult ones now had to be achieved under less propitious conditions: an executive branch that was less activist about civil rights, an increasing national preoccupation with controlling government costs and reducing federal bureaucracy, an increasingly diverse array of ill-defined "civil rights" responsibilities, and a generally less sympathetic public.²⁵

This author also states that organizational changes within the Department of Health, Education, and Welfare (HEW) accounted for the lack of attention paid to health care disparities. Civil rights compliance and monitoring responsibilities were removed from the parts of the agency that made decisions concerning the planning and financing of health care services.²⁶ Further, the author charged, the civil rights enforcement efforts of the agency were focused on education issues. Finally, the author states that "[t]he agency was so increasingly disengaged from direct monitoring and certification through delegation to state agencies, and was increasingly buried under a complex array of diverse and ill-defined responsibilities."²⁷

The 1970s

Despite efforts to implement and enforce title VI, discrimination continued in health care programs. For example:

Even as late as the 1970's, HEW found such blatant discrimination as segregated waiting rooms and different hours for black and white patients by physicians receiving HEW funds, inadequate minority representation on a State health planning council, use of "Mr.," "Mrs.," and "Miss" to address white but not black patients, and segregation in HEW-funded day care centers.²⁸

The Commission's 1970 review of HEW revealed that Federal civil rights enforcement activities continued to be weak. The Commission report stated:

HEW has had the most effective Title VI operation of any government agency. Nevertheless, over the years its compliance program has been uneven and has been marked by gaps and shortcomings. The extent to which HEW has been unable to fulfill its Title VI responsibilities is in large part a measure of the failure of the entire Federal effort. It is also a reflection of the complexity of Title VI enforcement and the intransigence of opposition to the letter and spirit of the law.²⁹

¹⁹ USCCR, *Title VI . . . One Year After: A Survey of Desegregation of Health and Welfare Services in the South*, 1966, pp. 7-10.

²⁰ *Ibid.*, p. 10.

²¹ *Ibid.*, p. 14.

²² New York State Advisory Committee to the U.S. Commission on Civil Rights, *Report on Buffalo: Health Facilities*, May 1964, p. 24.

²³ *Ibid.*, p. 22.

²⁴ Smith, "Addressing Racial Inequities in Health Care."

²⁵ *Ibid.*

²⁶ *Ibid.*

²⁷ *Ibid.*

²⁸ USCCR, *The Federal Civil Rights Enforcement Effort—1974*, November 1975, p. 116 (citations omitted) (hereafter cited as USCCR, *Enforcement Effort—1974*).

²⁹ USCCR, *HEW and Title VI: A Report on the Development of the Organization, Policies, and Compliance Procedures of the Department of Health, Education, and Welfare Under Title VI*

The Commission concluded that HEW's Office for Civil Rights (OCR) at that time was understaffed "in relation to the scope and complexity of its title VI obligations."³⁰ Further, OCR's reviews were too limited and infrequent. OCR had not reviewed extended care facilities, nursing homes, and other 24-hour health care facilities. Further, HEW did not adequately collect data for its compliance reports, nor did the agency place a high priority on complaints of discrimination.³¹ As such, discrimination continued in health care services.

In its 1970 report, *The Federal Civil Rights Enforcement Effort*, the Commission found that Federal efforts to enforce title VI continued to be inadequate.³² The report identified several deficiencies in title VI enforcement that are still relevant for many agencies today:

- Low status of Federal civil rights officials.
- Insufficient staff.
- Lack of clearly defined goals for civil rights activities.
- Isolation of civil rights programs from the rest of the agency.
- Passive enforcement actions.
- Failure to sufficiently use enforcement sanctions.
- Inadequate governmentwide coordination.³³

In a followup report 7 months later, the Commission stated that these problems continued to exist. For example, although HEW had made some progress, it conducted too few compliance reviews and pregrant reviews were done only on an ad hoc basis.³⁴ One year after the 1970 report, the Commission reported that HEW had made "marginal" progress; the Commission found no Federal agencies that had made good or even adequate progress in enforcing title VI.³⁵ HEW continued to have weak complaint investi-

gations, compliance reviews, and data collection programs.³⁶

The Commission next reviewed title VI implementation in 1973, and found results "dismayingly similar" to its previous reviews.³⁷ Regarding HEW programs, the Commission noted that HEW had developed effective tools for monitoring civil rights compliance, although it did not conduct a sufficient number of onsite compliance reviews. Much of this responsibility was being delegated to the States.³⁸ Two years later the Commission noted that there continued to be a "major gap" in title VI enforcement with regard to HEW programs. First, HEW did not consider physicians and other providers of health services under medicare's supplemental insurance benefits program to be covered by title VI. Second, title VI and other civil rights laws did not prohibit discrimination on the basis of sex.³⁹ Further, the Commission found that HEW failed to provide guidelines to recipients on their civil rights responsibilities, nor had it developed uniform guidelines for State agencies.⁴⁰ HEW also was deficient in reviewing State agencies, monitoring recipients of medicaid funds, conducting compliance reviews, and collecting racial and ethnic data.⁴¹ In fact, the Commission found that "complaint handling appears to be the principal compliance tool with which HEW has produced any positive results in the area of health and social services."⁴²

The Commission report revealed the types of discrimination that HEW continued to uncover in its role as an enforcement agency. For example, the Commission reported:

In January 1972, a black female surgeon had her privileges to practice surgery at [a hospital] in Bridgeport, Connecticut, terminated by that hospital. In her complaint filed with the OCR [Office for Civil Rights] in Region I, the surgeon alleged that she had been a victim of racial discrimination. [The hospital] responded that complainant was incompetent to perform surgery. In order to resolve the matter, HEW

of the Civil Rights Act of 1964, clearinghouse publication no. 22, 1970, p. 68 (hereafter cited as USCCR, *HEW and Title VI*).

³⁰ Ibid., p. 69.

³¹ Ibid., p. 72.

³² USCCR, *The Federal Civil Rights Enforcement Effort*, October 1970.

³³ USCCR, *The Federal Civil Rights Enforcement Effort: Seven Months Later*, May 1971, p. 3.

³⁴ Ibid., pp. 55-56.

³⁵ USCCR, *The Federal Civil Rights Enforcement Effort: One Year Later*, November 1971, p. xvii.

³⁶ Ibid., pp. 136-40.

³⁷ USCCR, *The Federal Civil Rights Enforcement Effort—A Reassessment*, January 1973, p. 2.

³⁸ Ibid., pp. 308-22.

³⁹ USCCR, *Enforcement Effort—1974*, pp. 118-20.

⁴⁰ Ibid., pp. 132-38.

⁴¹ Ibid., pp. 152-79, 190-97.

⁴² Ibid., p. 189.

employed two surgeons as medical consultants to investigate the charges and report their findings to OCR. Their report concluded that the hospital's position could not be substantiated by medical records and that the complainant had been treated differently from other surgeons because of her race. On September 12, 1974, OCR notified [the hospital] that it was in noncompliance with Title VI, and that failure to comply with Title VI could lead to administrative hearings and termination of all Federal funds if the hospital did not take steps within 30 days to come into compliance.⁴³

The Commission report revealed several other instances of discrimination that were found by HEW: exclusion of minority patients at a home health care center, segregated hospital facilities, and exclusion of minorities from a fraternal order that operated a hospital. Despite findings of discrimination, the Commission charged that HEW failed to properly pursue enforcement actions such as fund termination.⁴⁴

The Commission and its advisory committees performed other evaluations of discrimination in health care service delivery during the 1970s. In 1972 the Commission held a hearing on race relations in Cairo, Illinois, a city in southern Illinois that had seen much racial violence. Among its other findings, the Commission noted that health care in Cairo and the surrounding Alexander County was "totally inadequate, particularly for poor black families."⁴⁵ Black residents of Cairo reported that they were turned away from dentists' offices and referred to black dentists in other communities. In addition, there was only one hospital in Cairo and the surrounding county. The hospital operated a clinic, which was the only source of health care for poor people in the area. However, the clinic was about to lose money from HEW at that time, leaving the people of Cairo with no health care.⁴⁶ In response, the Commission recommended that HEW help smaller communities, like Cairo, to establish programs to meet the health needs "of those citi-

zens who currently receive inadequate, or in certain areas, no health care."⁴⁷

In 1975 the California Advisory Committee to the Commission issued a report on Asian Americans and Pacific Islanders in the health professions. The report examined State licensure policies for pharmacists, doctors, dentists, and nurses.⁴⁸ The advisory committee found that foreign-educated professionals had difficulty being licensed in the United States, despite immigration laws encouraging them to come to the country. The committee stated that when recently immigrated professionals applied for licensure, often their certifications were not recognized, their experience was not accepted, and/or their foreign educational credentials were not accepted.⁴⁹ In addition, pharmacists often were denied the opportunity to take licensing examinations. The advisory committee concluded that, due to the lack of health care professionals in many immigrant communities, the refusal to license doctors trained in other countries affected the services provided to minority communities.⁵⁰

Despite national attention to disparities in health care, discrimination and unequal access continued to affect the health care industry. In 1978 the Commission investigated discrimination against minorities and women in pensions and in health, life, and disability insurance. Because of its concern with how discrimination in the insurance industry affected the economic well-being of women and minorities, the Commission held a consultation with several experts in the areas of pensions and insurance.⁵¹ These experts provided several examples of discrimination in the health insurance industry:

- The exclusion of newborn infants from many medical expense policies in the first 14 to 30 days, which was "often mentioned as a form

⁴³ Ibid., pp. 184-86 (citations omitted).

⁴⁴ Ibid., pp. 202-09.

⁴⁵ USCCR, *Cairo, Illinois: A Symbol of Racial Polarization* (recommendations based on the Cairo Hearing, Mar. 23-25, 1972), February 1973, p. 27 (hereafter cited as USCCR, *Cairo*).

⁴⁶ USCCR, *Cairo, Illinois: Racism at Floodtide*, by Paul Good, clearinghouse publication no. 44, October 1973, pp. 49-55.

⁴⁷ USCCR, *Cairo*, p. 27.

⁴⁸ California Advisory Committee to the U. S. Commission on Civil Rights, *A Dream Unfulfilled: Korean and Pilipino Health Professionals in California*, May 1975, pp. 3-4.

⁴⁹ Ibid., p. 13.

⁵⁰ Ibid., p. 40.

⁵¹ USCCR, *Discrimination Against Minorities and Women in Pensions and Health, Life, and Disability Insurance*, consultation held in Washington, DC, Apr. 24-26, 1978, vol. I, Proceedings and Papers, pp. 1-2 (hereafter cited as USCCR, *Pensions and Insurance Consultation*, vol. I).

of sex discrimination because, in a sense, it's a discrimination against motherhood."⁵²

- Differential insurance for men and for women (e.g., women not permitted to buy long-term disability insurance).⁵³
- The lack of health insurance for conditions related to pregnancy and childbirth, the lack of maternity benefits for employees of small businesses, the exclusion of single women from maternity coverage, and excessive limitations and restrictions (such as a 10-month or longer waiting period before a person is covered, which would not cover a person in the event of a premature birth or miscarriage).⁵⁴
- "Blatant discrimination" against minorities in the life and health insurance industry in the form of employment conditions, availability of life and health insurance, and insurance premiums.⁵⁵

During the consultation, one expert concluded:

In general, the lower is current income, the poorer is the quality of the environment one inhabits and the more susceptible is one to disease, disability, and premature death. Thus, and conversely, the lower is current income, the greater is the need for protection against disease, disability, and premature death. Thus the paradox, the dilemma which blacks and other minorities must confront, and inasmuch as it is a dilemma created by society, it is one which can be resolved only by our society, rather than by one segment. If this sounds as if I am advocating some form of national provision for healthcare, I am.⁵⁶

In 1979 the Department of Education Organization Act⁵⁷ split HEW into two agencies: the U.S. Department of Education and the U.S. Department of Health and Human Services (HHS). The

Office for Civil Rights (OCR) at HHS was responsible for enforcing the civil rights statutes that prohibit discrimination by providers of health care and social services.⁵⁸ Without the educational component to exhaust available resources for civil rights enforcement, there should have been sufficient opportunity for the newly created HHS to ensure equal access to health care through its own enforcement efforts. Nonetheless, significant disparities in access to health care have persisted.

The 1980s and the New OCR

During the 1980s, the newly created OCR struggled with its civil rights enforcement responsibilities.⁵⁹ For example, OCR relied heavily on policies developed by the former HEW and developed few of its own policies.⁶⁰ The number of reviews that OCR conducted fell considerably after 1984, and the overall extent and quality of civil rights enforcement activity suffered significantly during the 1980s.⁶¹ According to one author, in 1980 it was hoped that the Office for Civil Rights of the new agency would be able to make a difference in health care for women and minorities. However, changes in the administration of the Federal Government eventually eroded the effectiveness of OCR. The author concludes, "By the end of the 1980s, an organization that had originally defined its roles as an advocate and prosecutor had been transformed into one that perceived itself as a passive, neutral arbiter of disputes that should avoid taking sides."⁶² Similarly, another scholar has stated that during the 1980s, there was a low priority on civil rights issues and, thus, "HHS/OCR effectively abdicated its title VI enforcement or compliance responsibilities."⁶³

As OCR floundered, discrimination continued. In April 1980, the Commission held a consultation on civil rights issues in health care de-

⁵² Statement of Herbert S. Denenberg, former Insurance Commissioner of Pennsylvania, in USCCR, *Pensions and Insurance Consultation*, vol. I, p. 4.

⁵³ *Ibid.*, pp. 7–9.

⁵⁴ Statement of Naomi Naierman, senior health analyst, ABT Associates in USCCR, *Pensions and Insurance Consultation*, vol. I, p. 89.

⁵⁵ Statement of David Abner III, professor of business administration, Howard University, in USCCR, *Pensions and Insurance Consultation*, vol. I, p. 97.

⁵⁶ *Ibid.*, p. 99.

⁵⁷ Pub. L. No. 96–88, 93 Stat. 669 (codified as amended at 20 U.S.C. §§ 3401–3510. (1994 & Supp. III 1997)).

⁵⁸ USCCR, *Funding Federal Civil Rights Enforcement*, clearinghouse publication no. 98, June 1995, p. 14.

⁵⁹ See USCCR, *Federal Title VI Enforcement to Ensure Non-discrimination in Federally Assisted Programs*, June 1996, chap. 5.

⁶⁰ *Ibid.*, pp. 224–25. See also chap. 3.

⁶¹ USCCR, *Federal Title VI Enforcement*, pp. 224–27.

⁶² Smith, "Addressing Racial Inequities in Health Care."

⁶³ Sidney Dean Watson, "Minority Access and Health Reform: A Civil Right to Health Care," *Journal of Law, Medicine & Ethics*, vol. 22, no. 2 (summer 1994), p. 130.

livery, which suggested important civil rights concerns remained nearly 20 years after the passage of the Civil Rights Act of 1964.⁶⁴ In its 1980 consultation, the Commission noted the specific civil rights responsibilities of HHS with respect to closings of federally assisted hospitals. The Commission observed:

Related to the issue of enforcement of civil rights laws is utilization of health care facilities and services. . . Particularly affected by accessibility to health care providers are inner-city or rural areas. Facilities in rural areas are often remote, resulting in both substantial travel time and long waiting periods by patients. In urban areas blacks tend to rely heavily on hospital emergency rooms and outpatient departments for regular care and are less likely to have a private physician. The closing or relocating of hospitals in urban areas can therefore have a devastating effect on health care received by inner-city residents. Ironically, it is in these areas that hospitals are most likely to be closed. . . A reason often given for such closings is that, since those areas with large minority populations are also less affluent and less financially able to sustain an ongoing hospital, the operation of the hospital is not efficient. . . Regardless of the reasons, hospital closings have a detrimental impact upon the quality of health care for those persons affected. If the hospitals are receiving Federal financial assistance, the Department of Health and Human Services has responsibility for ensuring that the people served continue to receive adequate health care.⁶⁵

The speakers at the consultation provided many examples of discrimination and disparities in health care:

- Segregated waiting rooms continued to exist, particularly in the South.⁶⁶
- Minority patients, regardless of income, were more likely than white patients to be treated by trainees rather than staff physicians.⁶⁷
- Minorities' symptoms were treated in isolation, without taking into consideration other health conditions.⁶⁸

⁶⁴ See generally USCCR, *Civil Rights Issues in Health Care Delivery: A Consultation Sponsored by the United States Commission on Civil Rights*, Apr. 15-16, 1980 (hereafter cited as USCCR, *Health Care Consultation*).

⁶⁵ *Ibid.*, p. xi.

⁶⁶ Sylvia Drew Ivie, Esq., executive director, National Health Law Program, statement in USCCR, *Health Care Consultation*, p. 33 (hereafter cited as Ivie statement).

⁶⁷ *Ibid.*

⁶⁸ *Ibid.*

- Minorities tended to be "overprescribed" with drugs and "oversurgeried."⁶⁹
- Physicians serving on the staffs of more than one hospital referred nonminority and minority patients to different hospitals.⁷⁰
- Hospitals required deposits for admission.⁷¹
- Women and minorities had difficulty obtaining health insurance.⁷²

One speaker stated that many people have died because of discrimination and their inability to obtain appropriate health care. According to the speaker, "The health status of minority people in this country is worse for every group from the cradle to the grave. It is worse in large part because of racial discrimination."⁷³ The Assistant Surgeon General at the time stated that blacks did not have equal access to care, and that "[b]eing black and without power means that the hospital in your community can close its doors and just go away."⁷⁴

With respect to hospital closures and minority communities, the Commission made the following recommendation:

The Office for Civil Rights at HHS, in conjunction with the Health Resources Administration, should develop procedures for examining hospital closures, (a) to determine the extent of negative impact their closure or relocation would have on the health care of minorities, older persons, and other low-income persons living in the area that the hospital services, and (b) to establish adequate alternative health care provisions for area residents before the hospital is closed or relocated. . . . [D]ecisions regarding closure or relocation must be weighed carefully and alternative health care provisions must be established.⁷⁵

⁶⁹ *Ibid.*

⁷⁰ Roma Stewart, former director, Office for Civil Rights (OCR), U.S. Department of Health and Human Services (HHS), statement in USCCR, *Health Care Consultation*, p. 41.

⁷¹ *Ibid.*, p. 40.

⁷² Marcia D. Greenberger, attorney, Center for Law and Social Policy, statement in USCCR, *Health Care Consultation*, p. 145.

⁷³ Ivie statement, p. 29.

⁷⁴ George I. Lythcott, former administrator, Health Services Administration, Assistant Surgeon General, Public Health Service, HHS, statement in USCCR, *Health Care Consultation*, p. 55.

⁷⁵ USCCR, *Health Care Consultation*, p. xv.

The Commission made several other recommendations aimed at increasing Federal oversight of health care systems, including expanding programs to encourage women and minorities to attend medical school and including civil rights concerns and civil rights compliance in all Federal programs dispensing funds for health care.⁷⁶

In 1980 the Commission again addressed inadequacies in HEW's enforcement program. The Commission focused on the Education Amendments of 1972. The Commission found that adequate data were not collected, investigations were insufficient, and an insufficient number of compliance reviews were conducted.⁷⁷ The Commission's recommendations, aimed at the then new Department of Education, remain relevant for today's HHS staff: improve OCR's data collection and analysis capacity, improve guidance and oversight of regional staff, allocate staff resources necessary to complete compliance reviews on schedule, increase cooperation with the Department of Justice, and increase title IX technical assistance and public information efforts.⁷⁸

The Commission took a second look at health insurance in 1982 and concluded that "[t]here is evidence that minorities and women do not share equally with majority men in the economic security afforded by employment in the insurance industry or by insurance protection against health risks."⁷⁹ According to the 1982 Commission report, minorities and women were at greater risk for certain health problems and therefore had greater difficulty in acquiring health insurance coverage than white males.⁸⁰ The report stated that minorities were less likely than whites to have health insurance; and women, except for married women, were less likely than men to have health insurance. The Commission concluded:

Discrimination these groups experience elsewhere, however, affects their health and socioeconomic condition and, given the institutional framework within

which insurance underwriting, marketing, and regulation take place, does operate to deny them equal access to insurance. For example, most health insurance is sold on a group basis and is acquired through employment. Minorities and women have higher unemployment rates than majority men. . . this avenue of obtaining insurance is available to disproportionately fewer women and racial and ethnic minorities, a fact that can be especially critical during an economic recession.⁸¹

The Commission predicted in 1982 that HHS and other Federal civil rights enforcement agencies would have difficulty achieving their missions without additional funding.⁸² In 1983 the Commission again evaluated the performance of Federal agencies and found that HHS faced resource constraints and policy problems that hindered its ability to perform its civil rights responsibilities.⁸³ The Commission noted that a proposed cutback in legal staff "suggests OCR plans to develop fewer cases that would meet standards necessary for enforcement action, although it formerly believed it should take more such action to relieve the burden on private litigants."⁸⁴ Further, the Commission also found that although HHS was "aware of many serious, even life threatening compliance problems, including numerous policies denying minority and handicapped persons hospital in-patient treatment, emergency care, and access to nursing homes," OCR only conducted compliance reviews for 0.08 percent of the health service facilities receiving Federal funds at that time.⁸⁵ The Commission also found deficiencies in OCR's enforcement of the block grant programs created in 1981. The Commission stated that this responsibility was "vitally important because large, relatively unrestricted Federal assistance programs historically have been particularly subject to civil rights abuses."⁸⁶

Health care issues also surfaced in the Commission's 1982 review of the Older Americans

⁷⁶ Ibid.

⁷⁷ USCCR, *Enforcing Title IX*, October 1980, pp. 13-14, 21, 24-25.

⁷⁸ Ibid., pp. 34-42.

⁷⁹ USCCR, *Health Insurance: Coverage and Employment Opportunities for Minorities and Women*, clearinghouse publication no. 72, September 1982, p. 1.

⁸⁰ Ibid., p. 2.

⁸¹ Ibid., p. 40.

⁸² USCCR, *The Federal Civil Rights Enforcement Budget: Fiscal Year 1983*, clearinghouse publication no. 71, June 1982.

⁸³ USCCR, *Federal Civil Rights Commitments: An Assessment of Enforcement Resources and Performance*, clearinghouse publication no. 82, November 1983, p. 43.

⁸⁴ Ibid., p. 49.

⁸⁵ Ibid., pp. 52-53.

⁸⁶ Ibid., p. 59.

Act.⁸⁷ Although the health service programs reviewed were funded under the Older Americans Act, not title VI, racial and ethnic disparities were found. The Commission found that older minorities were being underserved in almost all of the six cities included in the review.⁸⁸ The Commission's report revealed that older minorities faced barriers to participation due to transportation, not feeling welcomed in certain programs, location of programs outside minority communities, and language and cultural barriers.⁸⁹

In 1986 Congress held hearings on the effectiveness of OCR. The Chairman of the Subcommittee on Intergovernmental Relations and Human Resources at that time expressed concern that OCR relied too heavily on voluntary settlement. The Chairman stated that such remedies were "often inadequate."⁹⁰ He also stated that excessive delay in the handling of emergency cases was "particularly harmful because the discriminatory denial of service to an individual by a hospital, for example, can mean the difference between life and death."⁹¹ In general, the hearings revealed that OCR initiated few investigations, failed to resolve cases satisfactorily, and inadequately enforced civil rights laws.⁹² The management of OCR was also questioned.⁹³ A former director of OCR questioned the usefulness of settlement agreements, noting that OCR did not monitor such agreements effectively.⁹⁴ Another expert doubted the effectiveness of OCR's technical assistance program, absent adequate complaint investigation and compliance reviews:

⁸⁷ Pub. L. No. 889-73, 79 Stat. 218 (codified as amended at 42 U.S.C. §§ 3001-3057g (1994 & Supp. II 1996)).

⁸⁸ USCCR, *Minority Elderly Services: New Programs, Old Problems*, part II, November 1982, p. 4.

⁸⁹ *Ibid.*, pp. 51-52.

⁹⁰ *Hearings before a Subcommittee of the Committee on Government Operations, House of Representatives, 99th Cong.* (1986) (statement of Ted Weiss, Chairman, Subcommittee on Intergovernmental Relations and Human Resources of the House Committee on Government Operations, p. 2) (hereafter cited as OCR hearings).

⁹¹ OCR hearings (Weiss statement), p. 2.

⁹² OCR hearings (statement of Mervyn M. Dymally, Representative), p. 3.

⁹³ OCR hearings (Dymally statement), p. 3.

⁹⁴ OCR hearings (statement of Martin Gerry, president, M.H. Gerry, Co.), p. 32.

[U]nless you have an extensive and effective compliance review and complaint investigative process, there's not a great reason for the recipients of Federal financial assistance to come into voluntary compliance. There's got to be some feeling of inevitability, that at some point they'll be caught, to try to encourage them to take the steps, some of which may be costly and some of these costs may be minimized by effective technical assistance. But there's got to be some feeling of inevitability for that to move forward.⁹⁵

In April 1987, the Committee on Government Operations released its report based on the 1986 hearings and its investigation of OCR. The Committee identified several deficiencies in OCR's operations:

- OCR delayed case processing, which allowed discrimination to continue.
- Voluntary compliance agreements were insufficient to achieve compliance, did not secure adequate remedies, and were not monitored by OCR.
- Investigations were superficial and inadequate.
- OCR failed to advise regional offices on policies and procedures, even when requested.
- OCR did not formally charge recipients who were in violation of civil rights laws, and did not take cases to enforcement when negotiated settlement failed.
- OCR did not ensure that HHS policies were consistent with civil rights laws.
- OCR did not enforce the Hill-Burton community service assurance requirements of hospitals.
- The director of OCR at that time had misused Federal funds.⁹⁶

The Committee on Government Operations made several recommendations, many of which have not yet been addressed by OCR. These recommendations include the following: OCR should require that policies be developed for all possible violations, OCR should develop guidelines to ensure that voluntary compliance agreements achieve compliance, OCR should reinstate a quality review of cases, and OCR

⁹⁵ OCR hearings (statement of David F. Chavkin, directing attorney, Maryland Disability Law Center, Inc.), p. 36.

⁹⁶ *Investigation of the Office for Civil Rights in the Department of Health and Human Services*, H.R. REP. 100-56, at 5-38 (1987).

should be more aggressive in enforcing the community service assurance requirements of the Hill-Burton Act.⁹⁷

In 1988 the Commission held a hearing on public health policies and initiatives to control AIDS. In addition to issues related to disability and employment, several speakers discussed the disparate effect of AIDS on minority communities.⁹⁸ One expert stated that AIDS was one of the six leading causes of death for blacks. This speaker stressed the need for increased communication between minority communities and health professionals, minority institutions, and the Federal Government.⁹⁹ Another expert noted that AIDS is considered a "family disease" in Hispanic communities, and it is the "highest killer of women between the ages of 25 to 35," most of whom are Hispanic.¹⁰⁰ She also noted that over 90 percent of AIDS babies are black or Hispanic.¹⁰¹

Health Care Disparities in the 1990s

"After the last vestiges of gross discriminatory practices . . . have been abolished, the struggle for equal opportunity under Title VI will ultimately turn on the manner in which Federal programs are delivered and the extent to which they are utilized at the local level. In this respect the role played by top agency administrators and program managers will be decisive."¹⁰²

"The [HHS] Office for Civil Rights is an important, cross-cutting unit within HHS with a key mission and a number of difficult management challenges. At the time of HEW's split in 1980, the health and human service civil rights agenda had not been forcefully articulated. Since 1980, HHS's OCR has struggled to articulate the civil rights mission in the context of health and human service programs. And during this eighteen year period, investment in OCR as an organization has

declined dramatically all the while that civil rights issues and concerns have multiplied and become more complex. Today, OCR is a struggling organization facing many obstacles."¹⁰³

Thirty-five years after the passage of title VI, unequal access to health care remains a reality for many women and members of minority groups. There is still evidence of discrimination based on race, national origin, color, and gender in health care and health care related programs. Discrimination may be observed in the practice of racial medical redlining; the adverse effects of hospital closure and relocations to suburban communities on the minority population; national origin related issues, such as treatment of patients with limited English proficiency; unequal participation of minorities and women in medical research programs at university/teaching and other hospitals; and unequal access to health care financing programs such as medicare and medicaid.

For example, a 1990 report of the Connecticut Advisory Committee to the Commission examined southeast Asian refugees and their access to health and mental health services. Expert panelists stated that the unique circumstances of the refugees were not adequately taken into consideration by the health care industry. There were few health care professionals who could effectively address the social and cultural backgrounds of Southeast Asians, or effectively treat the depression and post-traumatic stress resulting from severe trauma experienced by the refugees.¹⁰⁴ One panelist gave an example of the types of discrimination faced by Southeast Asian refugees:

One woman, who [had] lost her first husband and seven children during the Pol Pot regime and who was tortured and raped, was hospitalized after threatening to kill herself; she was kept only a short time because she could not communicate and was told that long-term therapy was unavailable because the therapist refused to work through a translator.¹⁰⁵

⁹⁷ H.R. REP. 100-56, at 38, 39 (1987).

⁹⁸ USCCR, Civil Rights Aspects of Public Health Policies and Initiatives to Control AIDS, hearing held in Washington, DC, May 16-18, 1988 (hereafter cited as USCCR, *Initiatives to Control AIDS*).

⁹⁹ Herbert Nickens, Office of Minority Health, Public Health Service, HHS testimony in USCCR, *Initiatives to Control AIDS*, pp. 139-41.

¹⁰⁰ Elvira Rosales Arriola, assistant attorney general, New York State Department of Law, Civil Rights Bureau testimony in USCCR, *Initiatives to Control AIDS*.

¹⁰¹ *Ibid.*, p. 151.

¹⁰² USCCR, *HEW and Title VI*, p. 73.

¹⁰³ David Garrison, acting director, OCR, HHS, memorandum to the Deputy Secretary, HHS, Aug. 17, 1998, p. 2.

¹⁰⁴ Connecticut Advisory Committee to the U.S. Commission on Civil Rights, *Southeast Asian Refugees and Their Access to Health and Mental Health Services*, March 1990, p. 2 (hereafter cited as CT SAC Report).

¹⁰⁵ *Ibid.*, p. 3.

Another panelist questioned the lack of Federal action to assist refugees in the health care arena. According to the advisory committee report, this expert cited quick Federal action that had halted the sale of assault weapons to the general public when five Southeast Asian children were murdered in California, and "wondered what it would take to obtain similarly quick action on the resources needed to deal with the critical mental health needs of Southeast Asian refugees in [Connecticut]."¹⁰⁶

In 1992 the Commission produced a report titled *Civil Rights Issues Facing Asian Americans in the 1990s*.¹⁰⁷ The Commission cited, among other areas of concern, inadequate health care as a major civil rights issue for Asian Americans. Language and cultural differences pose particular barriers for Asian Americans, and can result in less effective health care services, or entirely unmet health care needs.¹⁰⁸ The report gives specific examples of how cultural misunderstanding, compounded by language barriers, hinders access to care. For instance, "A father was excluded from the treatment plan of his psychotic daughter because he believed that the spirits must be consulted before his daughter received medicine; the translator was ashamed of this belief and refused to communicate the father's concern. . . ."¹⁰⁹

As a result of the report's findings, the Commission made several recommendations for addressing the health care needs of Asian populations, including the collection of separate data for each major Asian American ethnic group which would improve the provision of culture-specific health care.¹¹⁰ The Commission also recommended that HHS should raise the priority given to increasing the number of trained health care professionals who have the linguistic and cultural skills necessary to serve immigrant Asian American communities.¹¹¹

¹⁰⁶ Ibid., p. 7.

¹⁰⁷ USCCR, *Civil Rights Issues Facing Asian Americans in the 1990s*, 1992.

¹⁰⁸ Ibid., pp. 163-67.

¹⁰⁹ Ibid., p. 165, citing Theanvy Kuoch, Khmer Health Advocates, as reported in CT SAC Report, p. 5.

¹¹⁰ Ibid., p. 202.

¹¹¹ Ibid., p. 203. For information about HHS' Asian and Pacific Islander Initiative, see USCCR, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. I. The Role of Governmental and*

Another State advisory committee report, issued in 1992, addressed health care issues. The New York State Advisory Committee noted that minority elderly are "among the most vulnerable members of society."¹¹² In a series of forums, the New York State Advisory Committee collected information from a variety of individuals and organizations concerned with health care and the minority elderly. Evidence was presented revealing that minority senior citizens were less likely than white senior citizens to have personal physicians and more likely to go to emergency rooms for medical care, thus running the risk of being denied medical care if the facility will not accept medicaid patients.¹¹³ Other speakers noted disparities favoring whites in the number of days spent in hospitals, vulnerability to certain diseases, and acceptance into nursing homes.¹¹⁴

In 1994 the National Institutes of Health (NIH) adopted a new policy on the inclusion of minorities and women in health research.¹¹⁵ Prior to this, the prevailing opinion had been that pregnant women, and women who were able to become pregnant (i.e., the majority of women), should be excluded from the potentially dangerous side effects of experimental drugs.¹¹⁶ However, much of the research at that time was conducted by white males using white males as test subjects. Recognizing that the results of such research may not be applicable to the general population, or to females and minorities, NIH revised its regulations to require the inclusion and consideration of minorities and women in research.¹¹⁷

The Commission's 1996 report, *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, found that the

Private Health Care Programs and Initiatives, September 1999, chap. 4 (hereafter cited as USCCR, *The Health Care Challenge*, vol. I).

¹¹² New York State Advisory Committee to the U.S. Commission on Civil Rights, *Minority Elderly Access to Health Care and Nursing Homes*, November 1992, p. 48.

¹¹³ Ibid., p. 4.

¹¹⁴ See generally *ibid.*

¹¹⁵ 59 Fed. Reg. 14,508 (1994).

¹¹⁶ R. Alta Charo, "Protecting Us to Death: Women, Pregnancy, and Clinical Research Trials," *St. Louis Law Journal*, vol. 35 (fall 1993), pp. 140-41. See USCCR, *The Health Care Challenge*, vol. I, chap. 3.

¹¹⁷ 59 Fed. Reg. 14,508 (1994).

HHS Office for Civil Rights had an inadequate civil rights implementation, compliance, and enforcement program. There was strong evidence that HHS was not enforcing title VI or ensuring that health care entities receiving billions of Federal dollars were carrying out title VI, title IX, and other Federal civil rights laws.¹¹⁸ The Commission also found OCR's outreach and education efforts were weak, its data collection was inadequate, and staff training was limited.¹¹⁹

The report offered several recommendations for improving HHS civil rights enforcement. Many of these were aimed at issuing guidance and policies on title VI. The Commission further recommended that HHS be more proactive in its enforcement activities by improving its preaward review process and conducting more indepth compliance reviews of recipients of Federal funds.¹²⁰ The Commission also recommended that OCR improve its processes for outreach activities, complaint investigations, monitoring State programs, and collecting data. Other recommendations included developing a comprehensive civil rights enforcement plan and conducting staff training on a regular basis.¹²¹

The extent to which women and members of racial and ethnic minorities face discriminatory actions resulting in unequal access to health care programs may be gauged by several indicators, including evidence provided by HHS' investigative actions and media and scholarly publications that illustrate the disparities. A review of current reports in the media, recently published scholarly articles, and other published reports containing statistical and/or anecdotal evidence suggests that health care discrimination against women and minorities is an epidemic that warrants further investigation and demands the attention of policymakers and providers alike.

One example of the recent media attention to disparities in health care is a 1998 *Newsday* series, "The Health Divide," which chronicled the differences in health care and health status for blacks and whites, comparing areas with substantial minority populations—Long Island and Queens, New York. In addition to disparities in health status, such as mortality and morbidity

rates, *Newsday* investigators found significant differences in treatment plans, facility usage, and subsequent outcomes. Among the study's findings were that whites get more intensive treatment than minorities; blacks often get more radical surgery than whites, when less severe alternatives are an option; blacks with serious kidney problems wait longer for transplants, and are less likely to receive a kidney than whites; "a chasm of culture and color" separates black patients from mostly white doctors; blacks in the areas surveyed have a mixed understanding of lifestyle risks for disease; and medical stereotypes about minorities persist.¹²²

Similarly, a recent article in the *New England Journal of Medicine* found that physician's recommendations may be influenced by the sex and race of the patient. A team of researchers at Georgetown University and other research facilities conducted a survey of physicians. Taking into account all factors, such as type of chest pain, level of coronary risk, and age, the researchers found that disparities in the physicians' recommendations for managing chest pain could be accounted for by race and gender differences among the patients.¹²³ Such findings are consistent with previous studies that had found differences in outcomes between men and women for certain conditions, such as heart attacks, suggesting that women received less vigorous treatments and were more likely to die than men as a result of a heart attack.¹²⁴

HHS itself has documented numerous complaints and compliance review investigations revealing civil rights violations in a variety of facilities, including hospitals, nursing homes,

¹¹⁸ USCCR, *Federal Title VI Enforcement*, pp. 242–46.

¹¹⁹ *Ibid.*, pp. 245–47.

¹²⁰ *Ibid.*, pp. 244–45.

¹²¹ *Ibid.*, pp. 245–49.

¹²² Ford Fessenden, "The Health Divide: A Difference of Life and Death for Blacks, Medical Care and State of Health Trail Whites," *Newsday*, Nov. 29, 1998, p. A-4. See also USCCR, *The Health Care Challenge*, vol. I, chap. 3.

¹²³ Kevin A. Schulman, Jesse A. Berlin, William Harless, Jon F. Kerner, Shyrl Sistrunk, Bernard J. Gersh, Ross Dube, Christopher K. Taleghani, Jennifer E. Burke, Sankey Williams, John M. Eisenberg, Jose J. Escarce, and William Ayers, "The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization," *New England Journal of Medicine*, vol. 340 (Feb. 25, 1999), pp. 618–26. See USCCR, *The Health Care Challenge*, vol. I, chap. 3.

¹²⁴ See Roberto Malacrida, Michele Genoni, Aldo Pietro Maggioni, Vito Spataro, Sarah Parish, Alison Palmer, Rory Collins, and Tiziano Moccetti, "A Comparison of the Early Outcome of Acute Myocardial Infarction in Women and Men," *New England Journal of Medicine*, vol. 338 (Jan. 1, 1998), pp. 8–14. See also USCCR, *The Health Care Challenge*, vol. I, chap. 3.

and treatment centers. Several compliance reviews and complaint investigations found a lack of interpreter services and failure to provide information to limited-English-proficient patients; other compliance reviews revealed disparities between the minority population of an area and the number of minority patients receiving health care from hospitals in the area. For example:

- An onsite compliance review revealed that a hospital was not in compliance with title VI and Hill-Burton regulations because it did not have Hill-Burton community assurance signs posted, nor did it provide appropriate translation and interpretation services.¹²⁵
- Another compliance review revealed that there was a disparity between the percentage of Hispanic and Asian American patients served at a hospital and the percentage of Hispanics and Asian Americans living in the hospital's primary service area.¹²⁶
- A limited scope review found that a senior center did not have any Hispanic patients, had difficulty in reaching the Hispanic population in its service area, and had failed to translate informational materials into Spanish.¹²⁷
- A complaint investigation revealed that there was sufficient evidence that a county health department failed to provide interpreter services. This finding resulted in a resolution agreement between OCR and the health department.¹²⁸
- In another complaint investigation, OCR found that a hospital had violated the community service provisions of the Hill-Burton Act¹²⁹ by failing to provide a patient emer-

gency treatment because her physician did not have staff privileges.¹³⁰

Oddly, the Commission's review of OCR's letters of findings revealed very few complaints or compliance reviews based on title VI and race issues, with the exception of issues relating to limited English proficiency.¹³¹ However, the scarcity of race-based complaints does not necessarily indicate the absence of discrimination on the basis of race and/or ethnicity. For instance, according to OCR's Region VIII manager, people who are discriminated against on the basis of race, color, or national origin are not filing complaints. Thus, there needs to be an increased awareness in the minority community of title VI issues.¹³² In addition, according to one legal expert, race discrimination is very subtle and patients often do not know they have been discriminated against.¹³³

One scholar has stated that the limitations of title VI itself and inadequate enforcement of title VI by HHS/OCR have led to the continuation of discriminatory policies and practices:

Enactment of Title VI ended the most blatant forms of health care discrimination. But Title VI has proved ineffective in ending the less obvious inequities caused by policies and practices that disproportionately adversely impact on racial minorities. Title VI's deficiencies are inherent in the structure of the statute: it relies on administrative enforcement; it fails to define statutorily prohibited discrimination and the evidentiary burdens in a case alleging discrimination because of disparate racial impact; it relies on voluntary receipt of federal funds; and it lacks monetary remedies in a private enforcement action.¹³⁴

Further, according to this author, during the 1980s, HHS/OCR "fail[ed] generally in its enforcement obligations" and "refused to investi-

¹²⁵ Michael R. Carter, deputy regional program manager, Region II, OCR, HHS, letter to Frank J. Maddalena, president and chief executive officer, Brookdale Hospital Medical Center, Brooklyn, NY, Feb. 27, 1997 (re: docket no. 02-95-7807), pp. 2-3.

¹²⁶ Charlotte Irons, regional manager, Region V, OCR, HHS, letter to Tom Kochis, administrator, Annapolis Hospital, Wayne, MI, Aug. 7, 1998 (re: docket no. 05987015), p. 1.

¹²⁷ Paul F. Cushing, regional manager, Region III, OCR, HHS, letter to Ronnie E. McLean, executive director, Barney Senior Center, Washington, DC, Dec. 6, 1996 (re: reference no. 03967424), p. 1.

¹²⁸ HHS, OCR, Region V and Lake County Health Department, Waukegan, IL, Resolution Agreement (re: docket no. 05973024), Feb. 21, 1997, p. 1.

¹²⁹ 42 CFR § 124.603(d)(1) (1998). The community service assurance requirements provides for services to be made available regardless of any grounds unrelated to the individ-

ual's need for service or the availability of the service at the facility.

¹³⁰ Paul F. Cushing, regional manager, Region III, OCR, HHS, letter to Richard Rohaley, chief executive officer, Jackson General Hospital, Ripley, WV, May 28, 1997 (re: docket no. 03973801), p. 1.

¹³¹ See chap. 4.

¹³² Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, telephone interview, Feb. 10, 1999, p. 4.

¹³³ Gordon Bonnyman, managing attorney, Tennessee Justice Center, Nashville, TN, telephone interview, Feb. 4, 1999, p. 9.

¹³⁴ Watson, "Minority Access and Health Reform," p. 130.

gate or pursue claims of racial and ethnic discrimination based on disparate racial impact.”¹³⁵ The author also charges that OCR’s “most fundamental enforcement shortcoming is its failure to collect and publish data on minority health access and barriers to access.”¹³⁶ The author states that OCR needs to collect data on the extent of racial segregation in hospitals, nursing homes, doctors’ offices, and managed care organizations.¹³⁷ This author concluded:

Thus, Title VI’s statutory reliance on administrative enforcement has proved misplaced, at least as regards federally funded health services. No administration has placed a high priority on minority health needs or the troubling inequities in health care delivery. The result has been, at best, inadequate and, at worst, a complete lack of health care civil rights administrative enforcement.¹³⁸

HHS/OCR has been neglectful by ignoring critical recommendations. As a result, the Federal Government’s goals of ensuring nondiscrimination and equal access to health care for minorities and women are far from being met. However, agency efforts to implement and enforce civil rights laws can be very effective in helping to address the current civil rights issues for women and minorities in the health care system. Unfortunately, a large part of the reason for the Federal Government’s failure to meet its goal of ensuring equal access to health care has been the largely ineffective, essentially lethargic civil rights enforcement efforts of HHS/OCR. With this report, the Commission more comprehensively evaluates HHS’ civil rights enforcement program and makes additional recommendations that, if adhered to immediately, would substantially improve OCR’s civil rights enforcement program.

A preliminary glance at discrimination in the health care delivery system relating to HHS/OCR’s implementation and enforcement of civil rights laws establishes the broad contours for the Commission’s current examination of HHS/OCR’s civil rights enforcement efforts. These issues include: evaluating the success of the agency’s overall implementation and enforce-

ment of these laws in ensuring equal access to health care for minorities and women generally and what can be done to more effectively implement and enforce the law with regard to specific issues such as unequal participation of women and minorities in medical research and hospital construction programs; racial medical “redlining,” or discriminating on the basis of race in directing patients to health care facilities; experiences of patients who are members of national origin minorities and whose English proficiency is limited; unequal access to health care financing programs; and other discrimination-related issues such as lack of continuity of care, overreliance on hospital outpatient departments and emergency rooms, and excessive length of waiting time for care.

Discrimination has never been eradicated completely from the health care industry, partly because of inadequate Federal efforts to eliminate inequality in health care delivery, research, and financing. As one scholar states:

The history of the evolution of health care and the monitoring of civil rights compliance offers little assurance that discrimination does not continue to play a role in accounting for some of the racial discrepancies in use and outcomes. In effect, there is no monitoring. The application of Title VI of the Civil Rights Act to health care was described at the time of the implementation of the Medicare program as a “potentially powerful engine of social change.” It never realized its potential and ran out of steam.¹³⁹

For 35 years, HHS (and its predecessor agency, HEW) have condoned policies and practices resulting in discrimination against minorities and women in health care. In many ways, segregation, disparate treatment, and racism continue to infect the Nation’s health care system. HHS has pursued a policy of excellence in health care for white Americans by medical physicians in a clinical setting, while it has stood by and allowed black Americans, Hispanic Americans, Native Americans, and Asian Americans to be treated with emergency care services by triage nurses and nurses’ assistants in a waiting room setting. HHS also has invested billions of dollars in scientific research for diseases and illnesses that are attributed to white males, but only a fraction of that for research on health is-

¹³⁵ Ibid.

¹³⁶ Ibid.

¹³⁷ Ibid., p. 131.

¹³⁸ Ibid.

¹³⁹ Smith, Health Care Divided, p. 321 (citation omitted).

sues pertinent to minorities and women. Further, HHS and Congress have closed their eyes to the millions of Americans who suffer from inadequate health care and lack of appropriate financing for health care.¹⁴⁰

Strong enforcement of title VI in the health care context is a matter of great urgency—it is, quite literally, a matter of life and death. HHS/OCR needs to examine its civil rights enforcement program and find a way to make it a strong, proactive force for ensuring civil rights compliance among the many HHS funding recipients across the country. A recent OCR complaint investigation highlights the urgency for such an effort: in 1996 a complainant alleged that a recipient of Federal funds discriminated against his mother on the basis of her disability, race, and age by providing substandard medical care. The complainant further alleged that as a result of this care, the patient died.¹⁴¹ This is not the only case in which a patient has died allegedly because of discriminatory care.

Health Care in the New Millennium

“Perhaps under the pretext of color blindness, many prefer not to look at what they do not see. Without concerted, sustained pressure this is unlikely to change. That pressure needs to be exerted both on agencies responsible for civil rights compliance and within the broader health services research community.”¹⁴²

There is little doubt that racial, ethnic, and gender disparities in health care will persist in the 21st century unless Federal enforcement of civil rights laws is strengthened. One author

succinctly states the condition of the health care industry as we approach our next millennium:

[T]he self-interest of individuals and institutions too often works to reinforce the effects of our deeply ingrained history. Concerned with losing private paying white patients that are key to their profitability, nursing homes find ways to influence admission practices and room assignments. Hospitals track the suburban flight of their medical staffs and the declining profitability of the payer mix in their service area and choose to relocate or expand operations in the suburbs. Managed-care plans run their own numbers, cherry-pick practices in predominately white, low per capita health insurance cost neighborhoods, and red-line high per capita insurance cost, often [in] predominately black neighborhoods. *Health care, as a result, becomes more racially divided and more unequal.*¹⁴³

Under the Commission mandate to evaluate Federal civil rights enforcement activities, the Commission turns its attention to the civil rights implementation and enforcement activities of the U.S. Department of Health and Human Services Office for Civil Rights. The Commission intends, through this report, to examine how well HHS/OCR is functioning in fulfilling its mandates to implement and enforce title VI of the Civil Rights Act of 1964;¹⁴⁴ title IX of the Education Amendments of 1972;¹⁴⁵ the Hill-Burton Act (title VI and title XVI of the Public Health Service Act);¹⁴⁶ and the nondiscrimination provisions of the Omnibus Budget Reconciliation Act of 1981,¹⁴⁷ from June 1994 to the present.

Therefore, in this report the Commission assesses the effectiveness with which OCR conducts the following: regulatory, policy, and investigative guidance documents; comprehensive

¹⁴⁰ See USCCR, *The Health Care Challenge*, vol. I, chaps. 2–3.

¹⁴¹ Marie A. Chretien, regional manager, Region IV, OCR, HHS, letter to complainant, Sept. 15, 1997 (re: complaint number 04-96-3200). OCR found the recipient not in violation of title VI for several reasons, although it did acknowledge that “OCR does not have the authority or expertise to determine the cause of death of [the patient].” *Ibid.* In other cases, OCR has closed the case after the complainant’s death, without further investigating the allegations of discrimination. John W. Halverson, regional manager, Region VII, OCR, HHS, letter to Kathy Heinson, administrator, Hope Care Center, Kansas City, MO, Mar. 13, 1998 (re: complaint no. 07972002), p. 1.

¹⁴² David Barton Smith, “The Racial Integration of Health Facilities,” *Journal of Health Politics, Policy and Law*, vol. 18, no. 4 (winter 1993), p. 866.

¹⁴³ Smith, *Health Care Divided*, p. 317 (emphasis added).

¹⁴⁴ 42 U.S.C. §§ 2000d–2000d–7 (1994).

¹⁴⁵ Pub. L. No. 92–318, title IX, 86 Stat. 235 (codified as amended at 20 U.S.C. §§ 1681–1688 (1994)).

¹⁴⁶ 42 U.S.C. §§ 291–291o (1994) (title VI of the Public Health Service Act); Pub. L. No. 93–641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q–300t (1994)) (enacting title XVI of the Public Health Service Act).

¹⁴⁷ Pub. L. No. 97–35, sec. 901, §§ 1908, 1918, sec. 2192(a), § 708, § 2606, § 677, 95 Stat. 357, 542, 551, 825, 900, 516 (codified as amended at 42 U.S.C. §§ 300x–7(a)(1)–(2); 300w–7(a)(1)–(2); 708(a)(1)–(2); 8625(a); 9906(a) (1994 & Supp. II 1996)). These laws contain provisions requiring nondiscrimination on the basis of race, color, national origin, sex, and religion.

onsite compliance reviews; processing of charges of discrimination under title VI and title IX; technical assistance, outreach, and education (and the success it has had in informing program recipients and beneficiaries, and the public at large as to rights and responsibilities under these laws); data collection in support of enforcement activities; oversight of State and local block grant and categorical funding recipients; and partnerships with other HHS agencies.¹⁴⁸ The report evaluates whether HHS/OCR has sufficient staff, resources, and training to carry out its responsibilities; whether its procedures and organization are effective; whether its policies and regulations comport with congressional intent and existing case law; and whether its policies, regulations, or the law require revision or elaboration in order to decrease the incidence and impact of discrimination in health care. Also, the report determines whether enforcement measures (i.e., compliance review, investigation, and litigation) taken by OCR adequately address pattern and practice systemic and individual complaints of discrimination. In addition, the report determines whether the education

and enforcement measures taken by OCR ensure compliance with the law, specifically whether standards and practices for monitoring consent decrees, settlements, and conciliation agreements are adequate.

Embedded throughout the report's analysis of these key aspects of the agency's civil rights implementation and enforcement activities is an evaluation of OCR's efforts with respect to current discrimination issues in health care service delivery, medical research programs, and health care financing programs. The report examines each of these issues in a variety of contexts. For example, chapters 2 and 3 of volume I of the report provide a statistical profile of health care for women and minorities; address the experiences of women and minorities relating to health care service delivery, health care financing, and medical research programs; and provide evidence of discrimination against women and minorities in these areas. In volume II, chapters 3 and 4 address these issues in the context of policy development, compliance reviews, data collection, and oversight of continuing State programs.

¹⁴⁸ Operating divisions of HHS are: the Administration on Aging, Administration for Children and Families, Agency for Health Care Policy and Research, Agency for Toxic Substances and Disease Registry, Centers for Disease Control and Prevention, Food and Drug Administration, Health Care Financing Administration, Health Resources and Services Administration, Indian Health Service, National Institutes of Health, and Substance Abuse and Mental Health Services Administration. See chap. 5.

Chapter 2

Organization and Administration of the U.S. Department of Health and Human Services

Civil Rights Responsibilities at HHS

OCR's Mission and Responsibilities

The Office for Civil Rights (OCR) is the U.S. Department of Health and Human Services (HHS) office primarily responsible for enforcing civil rights statutes. In its mission statement, HHS/OCR acknowledges the importance of the prevention of unlawful discrimination:

The Department of Health and Human Services, through the Office for Civil Rights, promotes and ensures that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination. Through prevention and elimination of unlawful discrimination, the Office for Civil Rights helps HHS carry out its overall mission of improving the health and well-being of all people affected by its many programs.¹

OCR serves as the HHS civil rights enforcement office and is responsible for ensuring that recipients of Federal financial assistance, such as hospitals and other health care facilities, research programs, and health care financing programs, do not discriminate against any individual on the basis of race, color, national origin, sex, disability, or age.²

To ensure against such discrimination, OCR implements and enforces title VI of the Civil Rights Act of 1964³ and titles VI and XVI of the Public Health Service Act, known as the Hill-Burton Act.⁴ OCR also enforces provisions of the Omnibus Reconciliation Act of 1981,⁵ which requires nondiscrimination on the basis of race, color, national origin, disability, age, sex, and/or religion in health care and block grant programs.⁶ While OCR does not have sole responsi-

amended at 42 U.S.C. §§ 291-291-o (1994)) (enacting title VI of the Public Health Service Act); Pub. L. No. 93-641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q-300t (1994)) (enacting title XVI of the Public Health Service Act); the nondiscrimination provisions of the Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, sec. 901, §§ 1908, 1918, sec. 2192(a), § 708, § 2606, § 677, 95 Stat. 357, 542, 551, 825, 900, 516 (codified as amended at 42 U.S.C. §§ 300x-7(a)(1)-(2); 300w-7(a)(1)-(2); 708 (a)(1)-(2); 8625(a); 9906(a) (1994 & Supp. II 1996)); and Title II of the Americans with Disabilities Act of 1990 (codified as amended at 42 U.S.C. §§ 12,131-12,165 (1994 & Supp. II 1996)). See U.S. Commission on Civil Rights (USCCR), *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, June 1996, p. 219 (hereafter cited as USCCR, *Federal Title VI Enforcement*). Section 504, the Age Discrimination Act, and the Americans with Disabilities Act will not be addressed because they are beyond the scope of this report.

³ 42 U.S.C. §§ 2000d-2000d-7 (1994).

⁴ 42 U.S.C. §§ 291-291-o, 300q-300t (1994).

⁵ Pub. L. No. 97-35, 95 Stat. 357 (codified as amended in scattered sections of 5, 7, 8, 10, 12, 15, 19, 20, 22, 23, 24, 25, 26, 29, 31, 33, 35, 36, 38, 42, 45, 46, 47, 49, 50 U.S.C (1994 & Supp. II 1996)).

⁶ 42 U.S.C. §§ 300x-7(a)(1)-(2); 300w-7(a)(1)-(2); 708 (a)(1)-(2); 8625(a); 9906(a) (1994 & Supp. II 1996). See Ronald Copeland, associate deputy director, Office for Program Operations; Marcella Haynes, director, Policy and Special Projects Staff; Pamela Malester, deputy director, Quality Assurance and Internal Control Division; OCR, HHS, interview in Washington, DC, July 29, 1998, p. 3 (statements of Copeland and Haynes) (hereafter cited as OCR interview, July 29, 1998). See also USCCR, *Funding Federal Civil Rights Enforcement*, clearinghouse publication no. 98, June 1995, p. 15 (hereafter cited as USCCR, *Funding Federal Civil Rights Enforcement*).

¹ U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), "Strategic Plan," Dec. 16, 1994, p. 5 (hereafter cited as HHS/OCR "Strategic Plan, 1994").

² HHS/OCR "Strategic Plan, 1994," p. 1. OCR is responsible for enforcing the civil rights provisions of Federal statutes pertaining to federally assisted and federally conducted programs such as: title VI of the Civil Rights Act of 1964, Pub. L. No. 88-352, title VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d-2000d-7 (1994)); section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1994 & Supp. II 1996); title IX of the Education Amendments of 1972, Pub. L. No. 92-318, title IX, 86 Stat. 373 (codified as amended at 20 U.S.C. §§ 1681-1688 (1994)); Age Discrimination Act of 1975, 42 U.S.C. §§ 6101-6107 (1994 & Supp. II 1996); titles VI and XVI of the Public Health Service Act, Pub. L. No. 79-725, 60 Stat. 1040 (1946) (codified as

bility for the enforcement of title IX of the Education Amendments of 1972,⁷ the act is applicable to medical schools and teaching hospitals that receive Federal funding.⁸ OCR does not have responsibility for HHS' internal equal employment opportunity program related to title VII of the Civil Rights Act of 1964.⁹

As the U.S. Government agency solely responsible for health care concerns in the Nation, HHS is responsible for ensuring that all Americans are afforded equal access to HHS-funded programs, free of discrimination. In addition to responding to complaints of discrimination, OCR is responsible for reviewing policies and practices for potential discriminatory effect on women and minorities, such as medical redlining, excessive wait times for care, unequal access to emergency care, requiring deposits before providing care, and lack of continuity of care. Further, OCR is responsible for addressing and eliminating overt discrimination, denial of services, and disparities in health care that can endanger the lives of patients, particularly women and minorities.

⁷ 20 U.S.C. §§ 1681–1688 (1994).

⁸ See *id.* See also Kathleen O'Brien, special assistant to the director and Patricia Mackey, deputy associate director, Office of Program Operations, OCR, HHS, interview in Washington, DC, Oct. 16, 1998, p. 5 (statement of O'Brien) (hereafter cited as O'Brien and Mackey interview). The Department of Education handles most of the title IX cases. Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy director; Valita Shepperd, deputy director, Program Development and Training Division; Ronald Copeland, associate deputy director; Johnny Nelson, deputy director, Voluntary Compliance and Outreach Division; Toni Baker, director, Investigations Division; Office of Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13 and 18, 1998, p. 3 (statement of Shepperd) (hereafter cited as OPO interview); Jeanette J. Lim, director, Program Legal Component, OCR, U.S. Department of Education, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 26, 1999 (re: coordination between HHS and DOEd on the enforcement of title IX). See also George Lyon, associate general counsel, Civil Rights Division, Office of General Counsel, HHS, interview in Washington, DC, Dec. 22, 1998, p. 5 (hereafter cited as OGC interview); Thomas E. Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 1, 1999 (re: coordination between HHS and DOEd on the enforcement of title IX). See chap. 3, for a discussion of regional experience with title IX.

⁹ Pub. L. No. 88–352, title VII, § 701, 78 Stat. 253 (codified as amended at 2000e–2000e–17 (1994)). See USCCR, *Federal Title VI Enforcement*, p. 219.

According to OCR staff, part of the work of OCR consists of conducting complaint investigations, compliance reviews, and pregrant reviews.¹⁰ Investigative and compliance work is primarily done in OCR's 10 regional offices. Complaints received in HHS operating divisions (OPDIVS)¹¹ should be forwarded to OCR.¹² However, there is no written policy directing OPDIVS to forward complaints to OCR,¹³ which could lead to a complaint not being handled properly or investigated in a timely manner. Compliance reviews can be limited scope (focusing on a particular area) or full scope (covering a broad statutory issue). Pregrant reviews focus on the civil rights program of applicants when they apply for funding for medicare programs.¹⁴ OCR, however, does not conduct preaward reviews of other applicants, which is a serious oversight. More proactive monitoring and interaction with applicants and recipients can prevent unlawful discrimination, help increase awareness and understanding of civil rights issues, and would make HHS more familiar with the policies and practices of applicants and recipients.

OCR's civil rights implementation and enforcement activities also include civil rights policy development and dissemination and initiation of enforcement actions against recipients who refuse to comply with civil rights requirements willingly.¹⁵ In addition, OCR undertakes proactive activities to promote civil rights compliance and uncover instances of noncompliance.

¹⁰ OCR interview, July 29, 1998, p. 3 (statements of Copeland).

¹¹ Operating divisions of HHS are: the Administration on Aging, Administration for Children and Families, Agency for Health Care Policy and Research, Agency for Toxic Substances and Disease Registry, Centers for Disease Control and Prevention, Food and Drug Administration, Health Care Financing Administration, Health Resources and Services Administration, Indian Health Service, National Institutes of Health, and Substance Abuse and Mental Health Services Administration.

¹² OCR interview, July 29, 1998, p. 4 (statements of Copeland).

¹³ Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, telephone interview, Feb. 10, 1999, p. 3 (hereafter cited as Kyle-Holmes interview).

¹⁴ OCR interview, July 29, 1998, p. 3 (statements of Copeland). Complaint investigations, compliance reviews, pregrant reviews, and technical assistance are discussed in detail in chap. 4.

¹⁵ See USCCR, *Federal Title VI Enforcement*, chap. 5.

Such proactive activities include conducting outreach and education to inform applicants, recipients, participants, and beneficiaries of HHS-funded programs of civil rights requirements; and providing technical assistance to recipients to help them comply with civil rights requirements.¹⁶ These activities are highlighted in HHS' regional annual operating plans.¹⁷

However, there are a variety of civil rights enforcement activities that OCR does not perform very well. Title VI policy development is seriously lacking, compliance reviews focus on narrow issues, and complaint investigations are often inadequate.¹⁸ Headquarters OCR has no direct authority over OPDIVS, and thus does not get involved in civil rights issues unless requested. Further, headquarters OCR appears to provide little oversight to regions in their day-to-day operations and does not coordinate activities across the regions. Similarly, there is a division of authority over the Civil Rights Division of the Office for General Counsel, resulting in little proactive work being done by that office.

Organization of Civil Rights Responsibilities at HHS

Overall, the organization of OCR is sufficient for carrying out civil rights enforcement activities, however there are some deficiencies. For example, there is no standard quality assurance program,¹⁹ and there are no staff specifically assigned to monitor civil rights issues and determine policy needs.²⁰ Further, staff do not specialize in and focus specifically on certain laws or classifications, such as title VI, gender issues, and Asian American issues.²¹ For example, when

the Indian Health Service (IHS) requested that a Native American specialist be assigned to OCR, the deputy director of the Office of Program Operations was assigned as a liaison to IHS, yet this did not seem to address IHS' concern that Native American "issues do not appear to have a high priority with the OCR."²²

Further, other offices and agencies that could assist OCR in enforcing civil rights laws do not have consistent contact with OCR.²³ Operating divisions do not incorporate civil rights concepts into many of their programs, and the Office of the General Counsel, Civil Rights Division does not actively participate in civil rights policy development. As such, OCR operates in a vacuum with little support from or interaction with other agency components.

Office for Civil Rights

*"OCR has not undertaken any reorganization since 1986, notwithstanding the uneven disruptions caused by the dependence on attrition. In Headquarters there are several units that have long since become too small to be sustainable as currently structured. There is a need to continue to shift staff from Headquarters to the field."*²⁴

In HHS the director of OCR reports directly to the Secretary and serves as the special assistant to the Secretary for Civil Rights.²⁵ The director is responsible for the overall operations of OCR, establishes civil rights policies and standards for civil rights compliance at HHS, and sets overall direction and priorities of OCR.²⁶ OCR consists of headquarters offices and 10 regional offices.²⁷ A deputy director and special

¹⁶ Ibid.

¹⁷ See discussion of annual operating plans under "Strategic Plans," below.

¹⁸ See chaps. 3 and 4.

¹⁹ OGC interview, p. 3; Paul Cushing, regional manager, Region III, OCR, HHS, telephone interview, Feb. 23, 1999, p. 5 (hereafter cited as Cushing interview).

²⁰ Marcella Haynes, director, Policy and Special Projects Staff, and Kathleen O'Brien, special assistant, OCR, HHS, interview in Washington, DC, Nov. 16, 1998, p. 2 (hereafter cited as PSPS interview).

²¹ Floyd Plymouth, Delores Braun, Gloria Silas-Webster, and Fay Dow, equal opportunity specialists/investigators, Region X, OCR, HHS, telephone interview, Feb. 2, 1999, p. 4 (hereafter cited as OCR Region X EOS interview). According to OCR headquarters staff, they are moving away from spe-

cialization toward a more team-oriented approach. OPO interview, p. 9 (statement of Copeland).

²² Michael E. Lincoln, acting director, Indian Health Service, Public Health Service, HHS, memorandum to Principal Deputy Assistant Secretary for Health, HHS, Mar. 11, 1994 (re: civil rights priorities).

²³ See also chap. 5.

²⁴ David Garrison, acting director, OCR, HHS, memorandum to the Deputy Secretary, HHS, Aug. 17, 1998, p. 4 (hereafter cited as Garrison memo).

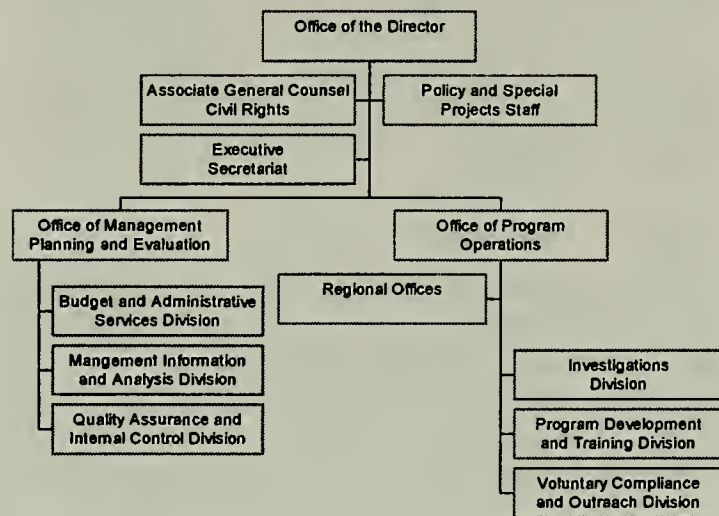
²⁵ USCCR, *Federal Title VI Enforcement*, p. 219.

²⁶ 51 Fed Reg. 41,154 (1986). A deputy director and a special assistant (to the director) assist the director in implementing the civil rights responsibilities. HHS, OCR, Organizational Chart, June 1998.

²⁷ HHS, OCR, Organizational Chart, June 1998.

assistant report directly to the director.²⁸ In addition to the Office of the Director, OCR's headquarters has five components: (1) the Executive Secretariat, (2) the Associate General Counsel/Civil Rights Division, (3) the Policy and Special Projects Staff, (4) the Office of Management Planning and Evaluation, and (5) the Office of Program Operations (see figure 2.1).

Figure 2.1
Organization of the HHS Office for Civil Rights



SOURCE: U.S. Department of Health and Human Services, Organization Chart, June 1998.

Executive Secretariat

The Executive Secretariat reviews documents forwarded for approval to the director, coordinates correspondence for OCR, coordinates assignments for the preparation of documents and responses, and maintains the director's official files.²⁹

Policy and Special Projects Staff

The Policy and Special Projects Staff develops civil rights policy and "[u]ndertakes special proj-

ects in program areas to provide guidance in implementation strategies for new or revised programs."³⁰ In addition, the Policy and Special Projects Staff monitors civil rights issues related to health and human services; maintains information on special policy issues; interprets policy for OCR components; and reviews HHS regulations, policies, and legislative proposals for civil rights sufficiency.³¹ This office also maintains liaison with other Federal civil rights enforcement agencies, coordinates the Interagency Report on Age Discrimination, and prepares publications and informational material.³²

Policy and guidance needs are determined in a variety of ways.³³ Complaints investigations and compliance reviews often reveal areas where more information and guidance is needed. In addition, meetings with OPDIVS and advocacy groups, news reports, and other sources provide feedback on the types of issues that need clarification. The Policy and Special Projects Staff works with the Office of Program Operations, the Office of General Counsel, and the Director's Office to determine policy needs.³⁴ However, few policy guidances have been written, and there is no systematic mechanism for issuing policy guidance on a regular basis.³⁵

The Policy and Special Projects Staff prepares a weekly information report that is sent to OCR senior staff and regional managers.³⁶ This "report" consists of copies of memoranda, reports, and other documents of interest to OCR.

³⁰ *Id.*

³¹ *Id.* According to the director of OCR, PPS staff also are involved on a number of departmental task forces and committees, such as the Departmental Minority Initiatives Steering Committee, the Departmental Minority Initiatives Coordinating Committee, the HHS Internet Committee, the HHS Consumer Protection Workgroup, the Ryan White Care Act Committee, and the American Indians/Alaska Natives Working Group. Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 5. See generally USCCR, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. I. The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999 (hereafter cited as USCCR, *The Health Care Challenge*, vol. I), chap. 4 for a discussion of HHS initiatives relating to civil rights and health care.

³² 51 Fed. Reg. 41,154, 41,155.

³³ PPS interview, p. 2.

³⁴ *Ibid.*, p. 2.

³⁵ *Ibid.*, p. 5. See chap. 3.

³⁶ PPS interview, p. 4.

²⁸ HHS, OCR, Position Description, deputy director; HHS, OCR, Position Description, special assistant; David Garrison, acting director, and Omar Guerrero, deputy director, OCR, HHS, interview in Washington, DC, Nov. 23, 1998, p. 1 (hereafter cited as Garrison and Guerrero interview). David Garrison became acting director of OCR on Mar. 2, 1998, and remained in the position for approximately 1 year. *Ibid.* Thomas Perez was appointed director of OCR in February 1999. Thomas Perez, director, OCR, HHS, interview in Washington, DC, June 1, 1999, p. 1 (hereafter cited as Perez interview).

²⁹ 51 Fed. Reg. 41,154, 41,155 (1986).

For example, a recent weekly information report included copies of an action memoranda to clear a *Federal Register* document, a draft report on cultural competency within HHS, a letter to the Secretary of State concerning resolutions passed by the General Assembly of the World Medical Association, *Federal Register* notices, and information from the Internet concerning employers' use of medical tests.³⁷ Other weekly information reports have included news clippings, articles, and other types of information.³⁸ Some of the information contained in the weekly reports is provided to headquarters by the regional offices.³⁹ However, there is no accompanying explanation of the attached documents or discussion of their importance to OCR. These reports need to be presented in a usable format; summaries and analyses of important civil rights information would be useful.

In addition, the Policy and Special Projects Staff develops publications, in coordination with the Office of Program Operations, to provide outreach and technical assistance.⁴⁰ However, the office has produced no new publications since the early 1990s, when fact sheets were developed on each of OCR's civil rights authorities. Since that time, OCR and the regions have been working to translate the fact sheets into the prominent languages spoken in the various regions.⁴¹ The director of the Policy and Special Projects office noted that budgetary restrictions have limited their ability to update and produce publications.⁴²

Another product of the Policy and Special Projects Staff is the compendium of OCR's title VI policy documents.⁴³ This collection includes copies of memoranda and letters concerning civil

rights issues. The documents are indexed in several ways (subjects, civil rights issue, program facility type, regulation citation) which facilitates their use.⁴⁴ However, these documents are often outdated and poorly copied. Summaries of the issues and positions in these documents, with citations to the actual documents, would be more useful.

Much of the work of the Policy and Special Projects Staff appears to be outdated, and many documents are in formats that render information difficult to use. Policy documents should be written and organized into usable policy documents on a continuing basis. This information must be organized and made available in a format that is easy for the general public to use and understand. Policies and issues should be summarized so that recipients and individuals clearly understand their rights and responsibilities under title VI, Hill-Burton, title IX, and other antidiscrimination laws and regulations.

Office of Management, Planning, and Evaluation

The Office of Management, Planning and Evaluation (OMPE) serves as the principal advisor in management policy, budget formulation, and automated data processing systems in OCR headquarters and the regions.⁴⁵ The office has three divisions. The Budget and Administrative Services Division formulates and executes OCR's budget.⁴⁶ OCR receives an allocation in the HHS budget, but does not have a separate budget for title VI enforcement or for the other civil rights authorities enforced by OCR.⁴⁷ This deficiency results in the inability to track their efforts to ensure that all civil rights statutes and regulations are properly monitored and enforced. By maintaining separate budget information for

³⁷ Marcella Haynes, director, Policy and Special Projects Staff, OCR, HHS, memorandum to OCR Senior Staff and Regional Managers I-X, Dec. 4, 1998 (re: weekly information report).

³⁸ Marcella Haynes, director, Policy and Special Projects Staff, OCR, HHS, memorandum to OCR Senior Staff and Regional Managers I-X, Oct. 23, 1998 (re: weekly information report).

³⁹ Ira Pollack, regional manager, Region IX, OCR HHS, telephone interview, Feb. 17, 1999, p. 2 (hereafter cited as Pollack interview).

⁴⁰ PSPS interview, p. 32.

⁴¹ Ibid.

⁴² Ibid., p. 33.

⁴³ See USCCR, *The Health Care Challenge*, vol. I, chap. 3.

⁴⁴ HHS, OCR, Policy and Special Projects Staff, "Title VI Policy Compendium," Vol. I (1984) and Vol. II (1985).

⁴⁵ 51 Fed. Reg. 41,154, 41,155 (1986). See also Marie Chretien, regional manager, Region IV, OCR, HHS, telephone interview, Feb. 9, 1999, pp. 1-2 (hereafter cited as Chretien interview); Chang interview, p. 2; Pollack interview, p. 3; Cushing interview, p. 5.

⁴⁶ 51 Fed. Reg. 41,154, 41,155 (1986).

⁴⁷ USCCR, *Federal Title VI Enforcement*, p. 222. See also Steve Melov, director, Management, Information, and Analysis Division, and Pamela Malester, deputy director, Quality Assurance and Control Division, Office of Management Planning, and Evaluation, OCR, HHS, interview in Washington, DC, Nov. 20, 1998, pp. 1-2 (statements of Melov) (hereafter cited as OMPE interview).

title VI activities, block grant activities, Hill-Burton activities, and title IX activities, OCR would be able to better plan and manage its policy development, compliance, and enforcement responsibilities.

OMPE's Quality Assurance and Internal Control Division develops and conducts an ongoing quality assurance program for field and headquarters components. This division assesses consistency, efficiency, and effectiveness in the application of procedures; directs research on recipient and beneficiary populations; and provides statistical analysis and research support for the recipient and beneficiary information needed throughout OCR.⁴⁸ According to the director of OCR, this division is responsible for a variety of internal control functions, including performance management and Federal Managers Financial Integrity and Accountability functions.⁴⁹ Division staff also develop OCR GPRA plans, respond to the HHS Accountability Report, and participate in cross-divisional teams, such as the team revising the *Case Resolution Manual*.⁵⁰

The Quality Assurance and Internal Control Division also is responsible for examining the administrative aspects of the regions.⁵¹ However, this division has little contact with the regions, and does minimal quality assurance on regional activities. Regional staff noted that they had not had recent contact with the Quality Assurance and Control Division, and the division had not recently conducted quality reviews of case files.⁵² For example, the Region II manager stated that formerly there were teams and guidelines for quality assurance, but this has not been done for about 10 years.⁵³ Another regional manager

noted that, overall, OCR does not do any studies to assess how sufficiently and effectively it enforces the civil rights statutes under their jurisdiction, but this is something that should be done.⁵⁴

The Management Information and Analysis Division maintains and disseminates the data processing information for all OCR components, and determines areas where needs could be met with data technology. It also conducts surveys and other studies, as well as evaluates the survey data.⁵⁵ An example of the work of the Management Information and Analysis Division is oversight and operation of the Case Activity Tracking System (CATS).⁵⁶ Information maintained by CATS includes compliance reviews, investigations, audits, pregrant reviews, types of facilities reviewed, case outcomes (alternative dispute resolution date, letter of findings issue date, etc.), statutes or authorities violated, issues, etc.⁵⁷ The CATS system is used to analyze workloads in the regions.⁵⁸ This division is also responsible for coordinating strategic and annual plans and conducting management studies.⁵⁹ However, this division did a poor job of coordinating the strategic plan with the Department to ensure that civil rights initiatives were integrated in the health care initiatives on minorities and women.⁶⁰

Office of Program Operations

The Office of Program Operations (OPO) manages OCR's program of civil rights compliance, including complaints investigations, voluntary compliance, and outreach activities. Essentially, the office serves as the principal advisor to the director in civil rights enforcement.⁶¹ It reviews cases recommended for enforcement and makes recommendations to the director and the

⁴⁸ 51 Fed. Reg. 41,154, 41,155 (1986).

⁴⁹ Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 6.

⁵⁰ *Ibid.*, p. 7.

⁵¹ Chretien interview, p. 4.

⁵² Cushing interview, p. 5.

⁵³ Carter interview, p. 2. Staff in this region hold regular case consultation meetings to address quality assurance issues. About every 3 weeks, usually during the course of an investigation, EOS staff and the regional attorney meet to discuss the cases on which they are working. In addition to these consultations, there is a team analysis of cases, sometimes second-level reviews of cases, but this is done case by case depending on the issue or other factors. *Ibid.*

⁵⁴ Chang interview, p. 13.

⁵⁵ 51 Fed. Reg. 41,154, 41,155 (1986).

⁵⁶ See HHS, OCR, *Case Activity Tracking System (CATS) Procedures Manual*, August 1998, p. 3 (hereafter cited as OCR, *CATS Procedures Manual*). CATS replaced the Case Information Management System in 1998. OCR, *CATS Procedures Manual*, p. 1.

⁵⁷ OCR, *CATS Procedures Manual*.

⁵⁸ 51 Fed. Reg. 41,154, 41,155 (1986).

⁵⁹ *Id.*

⁶⁰ See USCCR, *The Health Care Challenge*, vol. I, chap. 4.

⁶¹ 51 Fed. Reg. 41,154, 41,156 (1986).

Regional Offices

OCR's 10 regional offices report to the director of OCR through the Office of Program Operations (see figure 2.2).⁷² Approximately three-quarters of OCR's staff are located in its regional offices.⁷³ In each regional office, the Office of the Regional Manager "develops and delivers a comprehensive regional enforcement and voluntary compliance program to carry out the office mission."⁷⁴ The regional offices receive and investigate discrimination complaints; conduct compliance reviews to identify potential areas of non-compliance; coordinate voluntary compliance activities; and provide technical assistance and outreach to recipients, beneficiaries, and organizations.⁷⁵ However, most regional offices are not organized into separate divisions as is headquarters OCR. Region II staff stated that when the region had more resources there were more divisions, including a quality assurance division and an outreach unit.⁷⁶ However, currently, the re-

gions do not have enough resources to specialize their functions.⁷⁷

The civil rights managers in the regions report directly to the director of OCR, as is appropriate, although there is some contact between regional managers and regional directors. According to the regional OCR manager in Region II, occasionally, the regional manager will involve the regional director in an issue, out of courtesy, and the regional manager attends regular staff meetings with the regional director.⁷⁸ Some regions appear to have more interaction with the regional director than others. For example, the regional OCR manager for Region IV stated that she works "hand in glove" with the regional director in sharing information and providing input on each others' projects; however the regional director does not provide oversight to OCR's regional operations.⁷⁹

According to the director of OCR, although in the past OCR's budget did not allow regional office staff to visit other offices on a routine basis, there is now consistent interaction between headquarters and regional offices, and regional managers frequently confer with one another.⁸⁰ Regional managers communicate with one another, and headquarters has teleconferences with the regional managers.⁸¹ However, regional offices have little interaction with one another with regard to compliance reviews, complaint investigations, training, and outreach, education, and technical assistance.⁸² Only one example of regional coordination was provided. The Region IX manager stated that he had insufficient staff to conduct preaward reviews. Therefore, he worked with Region X to have the staff

⁷² OCR interview, July 29, 1998, p. 4. According to OCR, the regional managers may contact the director directly. However, organizationally, the associate deputy director for Program Operations is the direct supervisor of the regional managers. HHS, OCR, "Comments on the Commission Report," July 16, 1999, p. 2, transmitted via facsimile (hereafter cited as OCR, "Comments"). The 10 regional offices are in Boston, MA (Region I—Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont); New York, NY (Region II—New Jersey, New York, Puerto Rico, and the Virgin Islands); Philadelphia, PA (Region III—Delaware, the District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia); Atlanta, GA (Region IV—Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee); Chicago, IL (Region V—Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin); Dallas, TX (Region VI—Arkansas, Louisiana, New Mexico, Oklahoma, and Texas); Kansas City, MO (Region VII—Iowa, Kansas, Missouri, and Nebraska); Denver, CO (Region VIII—Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming); San Francisco, CA (Region IX—Arizona, California, Hawaii, Nevada, Guam, the Pacific Islands, and American Samoa); and Seattle, WA (Region X—Alaska, Idaho, Oregon, and Washington).

⁷³ HHS, OCR, "Position Management Control System, 09/13/98 thru 09/26/98," Oct. 10, 1998 (hereafter cited as OCR, "Position Management Control").

⁷⁴ 51 Fed. Reg. 41,154, 41,156 – 41,157 (1986).

⁷⁵ 56 Fed. Reg. 56,230 (1991); OCR interview, July 29, 1998.

⁷⁶ Mike Carter, regional manager, Region II, OCR, HHS, telephone interview, Feb. 2, 1999, p. 2 (hereafter cited as Carter interview); Arnold Loperena, Patricia Holub, and Victor Hidalgo, equal opportunity specialists, Region II, OCR, HHS, telephone interview, Feb. 3, 1999, p. 5 (hereafter cited as OCR Region II EOS interview).

⁷⁷ OCR Region II EOS interview, p. 2.

⁷⁸ Carter interview, pp. 1–2.

⁷⁹ Chretien interview, pp. 1–2; Pollack interview, p. 2; Cushing interview, p. 2.

⁸⁰ Thomas E. Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 7, 1999 (re: health care report), addendum, p. 2 (hereafter cited as Perez letter, July 7, 1999, addendum).

⁸¹ Carter interview, p. 7; Chretien interview, pp. 3–4; Pollack interview, p. 3; Velveta Golightly-Howell, regional attorney, Region VIII, OCR, HHS, telephone interview, Feb. 11, 1999, p. 1 (hereafter cited as Golightly-Howell interview).

⁸² Chretien interview, pp. 3–4; Ellen Miyasato, civil rights attorney, Region X, Office of the General Counsel, HHS, telephone interview, Feb. 2, 1999, p. 9 (hereafter cited as Miyasato interview).

Office of General Counsel.⁶² The office consists of three divisions:

- The Investigations Division oversees investigations that result from complaints, provides assistance to the regional offices, monitors investigation activities to determine program deficiencies, assesses investigative plans and letters of findings, and is the liaison between headquarters and regional offices to facilitate resolution of issues and policy questions.⁶³
- The Program Development and Training Division advises OCR on program planning and staff program training. It develops and directs all OCR program training for headquarters and field office personnel. The division identifies training needs, locates resources to meet those needs, identifies needs for procedure manuals, and develops and disseminates such documents for compliance activities. The division also provides leadership, guidance, and direction in the development and coordination of plans that identify civil rights objectives and establish priorities for attaining these goals.⁶⁴
- The Voluntary Compliance and Outreach Division oversees the compliance review program for recipients; provides assistance to regional offices for implementation of compliance policies; develops the intradepartmental technical assistance and outreach programs aimed at civil rights policy implementation; develops and manages the outreach programs and materials to constituent groups, recipients, and beneficiaries; and provides leadership and guidance in implementing civil rights responsibilities within the HHS OPDIVS. The division also facilitates communication of civil rights matters with other HHS offices, other Federal Departments, and State and local govern-

ments, including organizations representing such units of government, and advises recipients on the requirements for filing civil rights compliance assurance forms.⁶⁵

According to the director of OCR, OPO staff are involved in a number of projects that cross divisional lines. For example, staff in the Program Development and Training Division are heading a team to revise the *Case Resolution Manual* and develop the substantive compliance manual. They also are involved in several initiatives regarding issues such as the Temporary Assistance to Needy Families program and upgrading the agencies Intranet and Internet Web sites.⁶⁶ In addition, the Voluntary Compliance and Outreach Division provides technical assistance to HHS OPDIVS, reviews pregrant assurance information, and is involved in the pregrant automation project.⁶⁷

OPO has some interaction with the regional offices.⁶⁸ For example, if similar cases have been filed in different regions, OPO will coordinate among the regional offices. Further, OPO organizes case conference calls and reviews letters of finding (LOFs), when an LOF needs to be cleared through headquarters.⁶⁹ However, OPO appears to be more reactive than proactive. The office fails to maintain and aggressively implement annual training plans for its staff. Regional offices conduct outreach, yet outreach is not coordinated among the regions by the headquarters office.⁷⁰ Further, OPO provides little guidance and oversight for compliance reviews and complaint investigations.⁷¹ It is necessary that a central office coordinate among regional offices to ensure that the “best practices” developed in the field are followed by all regions.

⁶² *Id.*

⁶³ *Id.*

⁶⁴ *Id.* Currently, staff in this division are involved in a “massive effort to train approximately 2500 HCFA staff on the civil rights laws enforced by OCR and how those laws affect HCFA programs.” Perez letter, June 3, 1999, enclosure, “Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions,” p. 6. The division is also involved in planning Alternative Dispute Resolution training and investigative skills training for regional staff. *Ibid.*

⁶⁵ 51 Fed. Reg. 41,154, 41,156 (1986).

⁶⁶ Perez letter, June 3, 1999, enclosure, “Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions,” p. 5.

⁶⁷ *Ibid.*, enclosure, “Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions,” p. 8, and enclosure, “VCO Division Response to U.S. Civil Rights’ Commission Questions.”

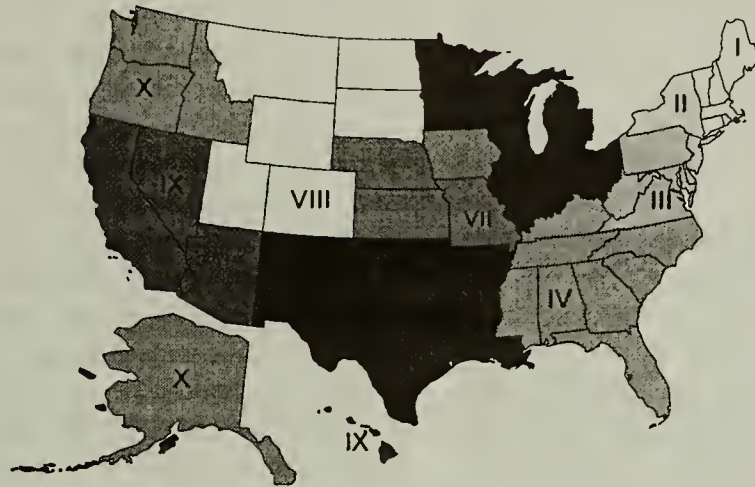
⁶⁸ Pollack interview, p. 3.

⁶⁹ *Ibid.*; Cushing interview, p. 6.

⁷⁰ OPO interview, p. 22 (statements of Mackey and Nelson).

⁷¹ O’Brien and Mackey interview, p. 7 (statement of O’Brien); OPO interview, pp. 30–33, 35–36, 43–44, 49–50 (statements of Mackey).

Figure 2.2
OCR Regions



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, "Regional Managers," undated document.

in that region conduct the Region IX preaward reviews.⁸³

Headquarters OCR oversees the regional offices, but appears to give them little guidance. For example, there is no formal method of directing technical assistance efforts in the regions;⁸⁴ OCR does not specify standard procedures for complaint intake and investigation;⁸⁵ and OCR does not get involved to a great extent in writing letters of findings, corrective action agreements, and compliance reviews.⁸⁶ Further, while the director of OCR identifies national priorities for enforcement, regional offices are free to fashion their own compliance and outreach programs.⁸⁷ In addition, OCR headquarters has little interaction with equal opportunity specialists (EOS) and attorneys in the regions.⁸⁸

Further, OCR conducts no quality assurance program in relation to regional operations, and the regions themselves have no formal quality assurance program.⁸⁹ Random checks and audits of regional activities are not conducted. However, headquarters periodically holds case consultation meetings (via telephone) with regional managers.⁹⁰ Absent a quality assurance program, with a systematic review of case findings and legal sufficiency review of letters of finding, OCR cannot ensure that cases are being closed properly.

The new director of OCR stated that he is taking steps to address some of these problems. He noted that, since his arrival at HHS in February 1999, he has focused on the regions both "substantively and organizationally."⁹¹ For ex-

⁸³ Pollack interview, p. 3. Recently OCR has developed several multiregional teams and task forces to address relevant issues such as limited English proficiency. These teams include the Racial Disparities Task Force and the Pregnant Automation Team. Perez letter, July 7, 1999, p. 2.

⁸⁴ OPO interview, p. 22 (statements of Mackey and Nelson).

⁸⁵ O'Brien and Mackey interview, p. 7 (statement of O'Brien).

⁸⁶ OPO interview, pp. 30–33, 35–36, 43–44, 49–50 (statements of Mackey).

⁸⁷ *Ibid.*, p. 30 (statement of Mackey).

⁸⁸ OCR Region VIII EOS interview, p. 10; OCR Region X EOS interview, p. 2. *See also* Fernando Morales, regional attorney, Region II, OCR, HHS, telephone interview, Feb. 3, 1999, p. 2

(hereafter cited as Morales interview); Roger Geer, regional attorney, Region VI, OCR, HHS, telephone interview, Feb. 3, 1999, p. 2 (hereafter cited as Geer interview). However, Region IV equal opportunity specialists stated that they felt interaction with OCR headquarters was good and that headquarters is responsive to their needs. Lloyd Gibbons, director of Voluntary Compliance and Outreach Division, Henry Barber, acting division director for Investigations, Region IV, OCR, HHS, telephone interview, Feb. 10, 1999, p. 3 (hereafter cited as OCR Region IV EOS interview).

⁸⁹ Kyle-Holmes interview, p. 3; Chang interview, p. 2.

⁹⁰ Kyle-Holmes interview, p. 3; Perez interview, p. 3.

⁹¹ Perez interview, p. 5.

ample, regional staff recently have been provided with information on investigation methods, redlining, and compliance methods. Further, teaming structures will be put into place, and the deputy director of OCR will travel to three regional offices to assist staff with creating teams and prioritizing, or “triaging,” complaints of discrimination.⁹²

Office of the General Counsel, Civil Rights Division

The Civil Rights Division of the HHS Office of the General Counsel (OGC) provides legal support and advice to OCR. While OCR provides funding for the salaries of attorneys in OGC who serve OCR, Civil Rights Division staff report directly to the General Counsel, not to the director of OCR.⁹³ The purpose of this arrangement is to ensure that there are adequate legal resources to carry out the substantial enforcement function of OCR and other agencies.⁹⁴ According to the associate general counsel for civil rights, it has not been established who has formal authority over the Civil Rights Division.⁹⁵ This is a serious oversight, resulting in the potential confusion of jurisdiction, and rendering the division devoid of the ability to take proactive steps in working with other offices within OCR.

The responsibilities of the Civil Rights Division include conducting legal sufficiency reviews and reviewing policy and other documents for legal accuracy.⁹⁶ There is a great deal of informal interaction between OCR and OGC staff, particularly at the regional level.⁹⁷ However, any proactive work done by the Civil Rights Division is done in conjunction with OCR; the Civil Rights Division does not initiate projects or inquiries, nor does it provide great input for the annual operating plans of the regional offices.⁹⁸ For example, OCR requested the assistance of OGC when drafting a guidance memorandum on limited English proficiency (LEP). In addition, OGC has commented on the annual operating

plans for the regional offices.⁹⁹ This reactive approach does not fully employ the legal skills available to OCR: OGC civil rights staff do not actively develop policy documents, provide technical assistance, or get involved in compliance reviews and complaint investigations.

Interaction between legal and investigative staff varies in the regions. Several of the attorneys interviewed by the Commission stated that they work closely with OCR investigators and often are involved with OCR investigations from start to finish.¹⁰⁰ Many said that they provide information and guidance to OCR investigators whenever requested or as needed.¹⁰¹ However, the regional attorney for Region VII stated that there is no direct line of communication between the regional investigative and legal staff. She stated that before the investigators contact her, they first go to the regional manager or a supervisor with the inquiry. The regional manager or supervisor will then contact the regional attorney.¹⁰² The Region IV manager stated that the headquarters Office of Program Operations acts as an intermediary between OCR regional managers and OGC headquarters' Civil Rights Division.¹⁰³

HHS Operating Divisions

HHS has 11 operating divisions: the Administration on Aging, Administration for Children and Families, Agency for Health Care Policy and Research, Agency for Toxic Substances and Disease Registry, Centers for Disease Control and Prevention, Food and Drug Administration, Health Care Financing Administration, Health Resources and Services Administration, Indian Health Service, National Institutes of Health, and Substance Abuse and Mental Health Services Administration.¹⁰⁴ Operating divisions have limited civil rights enforcement responsibilities, primarily consisting of reviewing applicants'

⁹² Ibid., pp. 5–6.

⁹³ OGC interview, p. 2. See also O'Brien and Mackey interview, p. 9 (statement of O'Brien).

⁹⁴ OGC interview, p. 2.

⁹⁵ Ibid.

⁹⁶ Ibid., pp. 3–4.

⁹⁷ Ibid., p. 2.

⁹⁸ Ibid.

⁹⁹ Ibid.

¹⁰⁰ Miyasato interview, p. 9; Golightly-Howell interview, p. 1; Geer interview, p. 2.

¹⁰¹ Morales interview, p. 2; Jean Simonitsch, regional attorney, Region VII, OCR, HHS, telephone interview, Feb. 8, 1999, p. 6 (hereafter cited as Simonitsch interview).

¹⁰² Simonitsch interview, p. 3.

¹⁰³ Chretien interview, p. 4.

¹⁰⁴ Operating divisions are discussed in greater detail in chap. 5.

statements of assurance that they will abide by applicable nondiscrimination laws and regulations.¹⁰⁵ Staff in the operating divisions with civil rights enforcement responsibilities are neither managed or guided by, nor do they report to, OCR. The director of OCR does not guide activities related to title VI, title IX, Hill-Burton, or the nondiscrimination requirements in block grant statutes and other external civil rights enforcement efforts conducted by operating division staff.¹⁰⁶ Further, OCR does not have a formal oversight and monitoring system to review, evaluate, and direct the performance of operating divisions as it relates to civil rights compliance activities. However, OCR does provide information and guidance to the operating divisions.¹⁰⁷

Workload and Staffing

*"OCR's search for its voice has been made all the harder as its 1980 staffing level of 550 FTE declined to today's total of less than 220 FTE, a 60% reduction in force. All of these reductions have occurred as a result of attrition, an unplanned shrinkage with uneven results for both Headquarters and each of the ten Regional Offices. . . . Prior to [February 1998] only a small number of new hires had been permitted in OCR and then only in some field offices as a few FTEs were transferred from Headquarters."*¹⁰⁸

OCR's staff size has diminished considerably over time, from 550 in 1980 to 225 in 1999.¹⁰⁹ OCR began implementing an "aggressive streamlining plan" during fiscal year (FY) 1994, which involved increasing the number of full-time equivalent positions (FTEs) allocated to the regions, reducing the number of headquarters

staff, and eliminating as many levels of management as possible in both the regions and the headquarters offices.¹¹⁰ OCR continues to reassign positions to the regional offices and authorized its regional offices to hire additional non-supervisory equal opportunity specialists during FY 1994. At the end of FY 1998, there were 59 full-time staff members and one part-time staff person in headquarters offices. Another 151 full-time, 1 part-time, and 1 temporary full-time staff persons were located in the regional offices (see table 2.1).¹¹¹

It is unclear why certain divisions of OCR are well-staffed compared with others. For example, there are nine staff members on the Policy and Special Projects Staff, yet little is done in the area of policy development.¹¹² Similarly, eight staff members in the Office of General Counsel are available to assist OCR, yet their role appears limited only to responding to OCR requests; their efforts are not proactive.¹¹³ However, although outreach is an important part of OCR's mission,¹¹⁴ there are only two staff members in the Voluntary Compliance and Outreach Division. With more staff, OCR could achieve its mission and oversee the regions more effectively. However, given its current staffing level, an uneven distribution of staff hinders OCR's efforts. Thus, it is crucial that OCR find ways to use its staff as effectively as possible.

According to the director of OMPE's Management, Information, and Analysis Division, some regions have a heavier complaint workload than others, and some regions have a heavier pregrant workload than others, which accounts for some of the differences in workload (see table 2.1).¹¹⁵ However, OCR noted that the production and workload measurement system used by OCR sets measures to assess investigators' workload including all types of case activities (complaints, postgrant reviews and investigations, pregrant reviews and monitoring activities) on an investigated complaint equivalency basis. Thus using the OCR measurement sys-

¹⁰⁵ O'Brien and Mackey interview, p. 8 (statement of Mackey). See also Ron Copeland, director, Office of Program Operations, and Kathleen O'Brien, special assistant, OCR, HHS, interview in Washington, DC, Nov. 13, 1998, p. 2 (statement of Copeland); Kathleen O'Brien, special assistant to the director, OCR, HHS, interview in Washington, DC, Nov. 13, 1998, p. 2 (hereafter cited as O'Brien interview). See also PSPS interview, p. 7.

¹⁰⁶ O'Brien interview, p. 1.

¹⁰⁷ O'Brien and Mackey interview, p. 8 (statement of O'Brien).

¹⁰⁸ Garrison memo, p. 2.

¹⁰⁹ HHS, OCR, "OCR Budget and FTE Usage History, FY 80-FY 99 est.," Oct. 5, 1998 (hereafter cited as OCR, "Budget and FTE Usage History").

¹¹⁰ USCCR, *Federal Title VI Enforcement*, pp. 222-23.

¹¹¹ Perez letter, July 7, 1999, p. 4; see also OCR, "Position Management Control."

¹¹² See chap. 3.

¹¹³ OGC interview, p. 2.

¹¹⁴ HHS/OCR, "Strategic Plan, 1994," p. 5.

¹¹⁵ OMPE interview, p. 5 (statement of Melov).

Table 2.1
Number of OCR Staff Members by Office and Regional Workload, 1998

Office/Division	Full-Time staff	Part-Time/temporary staff	Regional workload per EOS	Regional complaint workload per EOS	Regional workload per EOS*
Office of the Director	4	0	N/A	N/A	N/A
Policy and Special Projects Staff	9	0	N/A	N/A	N/A
Office of Management, Planning, and Evaluation			N/A	N/A	N/A
Quality Assurance and Internal Controls Division	4	0	N/A	N/A	N/A
Management Information and Analysis Division	6	0	N/A	N/A	N/A
Budget and Administrative Services Division	5	0	N/A	N/A	N/A
Office of Program Operations	4	0	N/A	N/A	N/A
Investigations Division	8	0	N/A	N/A	N/A
Voluntary Compliance and Outreach Division	2	1	N/A	N/A	N/A
Program Development and Training Division	9	0	N/A	N/A	N/A
General Counsel	8	0	N/A	N/A	N/A
Region I (Boston)	14	0	17.11	18.90	61.93
Region II (New York)	9	0	17.27	33.60	66.80
Region III (Philadelphia)	17	1	13.34	12.86	40.33
Region IV (Atlanta)	21	0	15.86	21.79	94.57
Region V (Chicago)	19	0	17.60	23.54	82.92
Region VI (Dallas)	22	0	30.14	23.59	121.09
Region VII (Kansas City)	13	1	17.61	26.55	80.12
Region VIII (Denver)	11	0	16.47	20.77	52.62
Region IX (San Francisco)	14	0	26.14	46.88	119.36
Region X (Seattle)	11	0	14.66	25.80	67.80
Total	210	3	18.75	24.55	81.72

* Total caseload without weighting

SOURCES: U.S. Departments of Health and Human Services, Office for Civil Rights, "Position Management Control System, 09/13/98 thru 09/26/98," Oct. 10, 1998, and Thomas E. Perez, director, Office for Civil Rights, U.S. Department of Health and Human Services, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, U.S. Commission on Civil Rights, July 7, 1999 (re: health care report), addendum, p. 5.

tem, each investigator handled the equivalent of approximately 19 investigated complaints. Based on a simple count of cases, each equal opportunity specialist had an average workload of 82 cases of all types, including 25 complaints. None of these figures include outreach initiatives.¹¹⁶

The regional offices have limited staffing and resources.¹¹⁷ The number of staff persons in each regional office differs greatly—from 9 staff

members (in Region II) to 22 staff members (in Region VI). Differences in the number of staff within the regional offices are due primarily to attrition.¹¹⁸ As a result of uneven staffing, the average workload per staff is uneven in the regions. Data for FY 1998 indicate that Regions II and IX, among those with the fewest employees, had the highest total complaint workload per equal opportunity specialist (EOS), at 33.62 complaints and 46.88 complaints per EOS, respectively.¹¹⁹ Regions I and III had the fewest complaints per EOS—18.90 and 12.86, respectively. The two regions with the highest number of employees, Regions IV and VI, had complaint

¹¹⁶ Perez letter, July 7, 1999, addendum, p. 4; see also OMPE interview, p. 5.

¹¹⁷ OCR Region II EOS interview, p. 7; Chretien interview, p. 13; OCR Region VIII EOS interview, p. 10; Golightly-Howell interview, p. 10; Chang interview, p. 13; Pollack interview, p. 10; OCR Region IX EOS interview, p. 7; Freeman interview, p. 11; John Halverson, regional manager, Region VII, OCR, HHS, telephone interview, Feb. 12, 1999, p. 9 (hereafter cited as Halverson interview).

¹¹⁸ Garrison and Guerrero interview, p. 2 (statement of Garrison).

¹¹⁹ Perez letter, July 7, 1999, addendum, p. 5.

workloads similar to the national average of 24.55 complaints per EOS. Region IV had 21.8 complaints per EOS; Region VI had 23.60 complaints per EOS.¹²⁰

All but two regions experienced slight declines in the number of equal opportunity specialists between FY 1997 and FY 1998, while only half of the regions experienced an increase in "investigated complaint equivalent workload" (total workload) per EOS.¹²¹ Overall, on a national basis, there was a 4 percent decline in investigated complaint equivalent workload per EOS.¹²² However, Region III staff noted that although the complaint workload has decreased, the nature of the complaints has become more complex, thus requiring more investigation time.¹²³ Similarly, the Region IX manager stated that although the number of employees has decreased, the workload has remained the same.¹²⁴ He stated that his office is more efficient than it used to be, but not efficient enough to cover every issue. Because of their heavy complaint workload, Region IX staff do not have the resources to conduct other enforcement activities, such as researching civil rights issues.¹²⁵

To carry out a vigorous civil rights program that includes comprehensive onsite compliance reviews and increased outreach, education, and technical assistance (to potential applicants, beneficiaries, participants, recipients, and program administrators) additional staff and resources obviously are needed both at headquarters and in the regions. Further, additional staff are needed for developing appropriate policy guidance and training for civil rights staff and program administrators. Although several regional staff members have stressed the need for additional staff,¹²⁶ OCR did not provide suffi-

cient evidence to the Commission that it had requested more staff, or that it had conducted a detailed analysis of the need for additional resources. Although OCR maintains that it has experienced a devastating decline in the number of employees,¹²⁷ it has failed to appropriately account for the effect the decline in employees has had on the operations of OCR. OCR discusses attempts to realign its staff in the region by shifting vacancies from headquarters to regional offices;¹²⁸ however, OCR failed to provide documentation of the need to hire more staff. Lacking a detailed analysis of the repercussions of an inadequate staff, OCR will find it difficult to convince Congress that additional staff are needed. In fact, the data provided to the Commission indicated that workloads have decreased in some regional offices, suggesting that additional staff are not necessarily needed in the regions.¹²⁹ Given the uncertainty that OCR will receive a funding increase, the Commission has identified several areas where OCR needs to make better use of the resources it has by appropriating them more efficiently.

Past Performance and Recent Initiatives on Civil Rights Enforcement

OCR's History and Past Performance

The U.S. Department of Health, Education and Welfare (HEW) was created by Reorganization Plan No. 1, which President Dwight D. Eisenhower transmitted to the Congress on March 12, 1953.¹³⁰ In 1979 the Department of Education Organization Act¹³¹ reorganized the Department of Health, Education and Welfare into two separate Federal agencies, the Department of Education and the Department of Health and Human Services (HHS). The Office for Civil Rights (OCR) at HHS became responsible for enforcing the civil rights statutes that prohibit

¹²⁰ Ibid.

¹²¹ Ibid.

¹²² Ibid. In July 1999, OCR indicated that through May 31, 1999, complaints had been received at a rate that is 32 percent higher than through the same time the previous year. Ibid., pp. 5-6.

¹²³ Jane Rogers, Kathleen Femple, and Laureen Shembry, equal opportunity specialists, Region III, OCR, HHS, telephone interview, Feb. 24, 1999, p. 7 (hereafter cited as OCR Region III EOS interview).

¹²⁴ Pollack interview, p. 8.

¹²⁵ Ibid.

¹²⁶ OCR Region III EOS interview, p. 7; Chang interview, p. 13; Pollack interview, p. 10; Halverson interview, p. 9; Chre-

tien interview, p. 13; OCR Region VIII EOS interview, p. 10; OCR Region IX EOS interview, p. 7; Roosevelt Freeman, regional civil rights attorney, Region IV, Office of General Counsel, HHS, telephone interview, Feb. 10, 1999, p. 11 (hereafter cited as Freeman interview).

¹²⁷ Garrison and Guerrero interview, p. 1.

¹²⁸ Ibid., p. 2.

¹²⁹ OCR, "1998 Mid-Year Workload," p. 2.

¹³⁰ Reorganization Plan No. 1 of 1953, Apr. 1, 1953, chap. 14, 67 Stat. 18 (codified at 42 U.S.C. § 3501 (1994)).

¹³¹ Pub. L. No. 96-88, 93 Stat. 669 (codified as amended at 20 U.S.C. §§ 3401-3510 (1994 & Supp. III 1997)).

discrimination by providers of health care and social services.¹³²

Following the split, HHS/OCR's civil rights enforcement efforts were largely ineffective.¹³³ OCR relied heavily on policies developed by the former HEW. There was almost no policy development by HHS after 1981.¹³⁴ In addition, the number of compliance reviews that OCR conducted fell considerably after 1984.¹³⁵ Overall, the extent and quality of civil rights enforcement activity suffered so significantly during this period, that the Secretary charged an intradepartmental team to review civil rights implementation.¹³⁶ The HHS Civil Rights Review Team found that, because the focus of HEW's office for civil rights had been on education, the HHS OCR was "lacking health and human service civil rights policies, precedents, standards and procedures by which it could operate effectively."¹³⁷ In addition, the team's 1993 report identified several areas of deficiency, including:

- The mission of OCR was not well defined.
- Complaint handling varied depending on who investigated the complaint.
- Staff were inadequately trained.
- Regions often did not share information on complaint processing.
- Complaints were closed prematurely.
- Monitoring of corrective action agreements was uneven.
- The headquarters office did not effectively provide direction to the regional offices.¹³⁸

To remedy these problems, the civil rights review team recommended that: (1) OCR clarify its mission and develop a strategic plan, (2) OCR reform the complaint process and develop consistent criteria for determining civil rights compliance, (3) OCR, operating divisions, and States more effectively share civil rights responsibilities,

and (4) OCR implement more outreach activities.¹³⁹

A 1992 HHS Office of Inspector General (OIG) review of OCR's Hill-Burton program found additional deficiencies in OCR's approach to civil rights enforcement. For example, the OIG found that OCR had limited authority to enforce the Hill-Burton regulations and no formal or uniform procedures were in place to follow-up on corrective action agreements and ensure that facilities were in compliance.¹⁴⁰ The OIG recommended that OCR develop a system to monitor compliance agreements, conduct unannounced visits to Hill-Burton facilities to review their compliance with the law, and determine whether regional guides and methodologies could be shared by all regional offices. In addition, the OIG recommended that OCR seek legislative authority that would allow it take administrative action against facilities that fail to comply with the Hill-Burton Act.¹⁴¹ Little action has been taken to address the OIG's recommendations. For example, not all regions conduct unannounced visits, and no action has been taken to increase OCR's authority to enforce the Hill-Burton regulations.¹⁴²

Although OCR has not addressed the OIG's concerns, it has implemented some of the recommendations of the Civil Rights Review Team. OCR prepared a strategic plan in 1994, and has attempted to streamline its complaint intake process by determining up front which complaints should receive the highest priority.¹⁴³ In addition, OCR has striven to create partnerships with States and OPDIVS and has focused on technical assistance and outreach activities to both partners and the recipients of health care services.¹⁴⁴ However, these activities have not resolved completely the problems that OCR faced in the 1980s. In addition, training remains insufficient for all OCR staff; and compliance

¹³² USCCR, *Funding Federal Civil Rights Enforcement*, p. 14.

¹³³ See *ibid.*, chap. 5. See also chap. 1, for a history of HHS/OCR's ineffective civil rights enforcement record.

¹³⁴ See *ibid.*, pp. 224–25. See also chap. 3.

¹³⁵ USCCR, *Federal Title VI Enforcement*, p. 227.

¹³⁶ *Ibid.*, p. 224.

¹³⁷ HHS, *Report of the HHS Civil Rights Review Team*, September 1993, p. 1 (hereafter cited as HHS, *Civil Rights Review Team Report*).

¹³⁸ *Ibid.*, pp. 6–10.

¹³⁹ *Ibid.*, p. 12.

¹⁴⁰ HHS, Office of Inspector General, *Office for Civil Rights' Oversight of the Hill-Burton Program*, OIG-05-90-00261, August 1992, pp. 6–7 (hereafter cited as OIG, *OCR's Oversight of Hill-Burton*).

¹⁴¹ *Ibid.*, pp. 8–9.

¹⁴² Kyle-Holmes interview, p. 6.

¹⁴³ See "Strategic Plans," below for information on the OCR strategic plan; see chap. 4, for a discussion of complaint intake procedures.

¹⁴⁴ See HHS/OCR "Strategic Plan, 1994."

reviews, complaint intake, investigations, and monitoring of corrective action agreements are conducted in different manners, depending on the issues involved and the resources available, thus resulting in an uneven application of civil rights requirements. For example, different types of data are collected, monitoring lasts for varying amounts of time, and different approaches are taken for outreach, education, and technical assistance.¹⁴⁵

In a 1996 report on Federal title VI enforcement, the U.S. Commission on Civil Rights found that HHS still had not published title VI guidelines and had issued few policy directives. In addition, the Commission noted that OCR continued to lack a comprehensive preaward review process, conducted few postaward desk audit reviews and comprehensive onsite compliance reviews, had an increasing complaint backlog, and lacked a comprehensive system for monitoring corrective action commitments.¹⁴⁶ Further, the Commission recommended that OCR improve its technical assistance and outreach efforts, improve its oversight of operating divisions and State-administered grant programs, improve its data collection and analysis systems, and provide regular staff training.¹⁴⁷ Currently, OCR conducts preaward reviews only of facilities applying to the medicare programs, and its compliance review activities are limited.¹⁴⁸ HHS/OCR have ignored the Commission's recommendations and continues to operate an ineffective and extremely weak civil rights enforcement program.

Recent Initiatives

In 1994 OCR developed a strategic plan for civil rights enforcement throughout the Department.¹⁴⁹ This plan remains in effect today. The FY 1999 Annual Performance Plan, developed in accordance with the Government Performance and Results Act (GPRA),¹⁵⁰ flows directly from

the strategic plan.¹⁵¹ Annual operating plans (AOPs) combine the goals stated in the strategic plan, obligations under the GPRA Annual Performance Plan, and other initiatives.¹⁵² In addition, HHS (and all agencies with civil rights enforcement responsibilities) are required to submit an annual implementation plan for title VI to the Department of Justice.¹⁵³ These plans are interrelated.¹⁵⁴ Yet they also appear to be duplicative of each other.

Strategic Plans

OCR Strategic Plan

The OCR strategic plan was developed in 1994 and has not been reissued since then.¹⁵⁵ The plan identifies OCR's goals for civil rights enforcement throughout the Department.¹⁵⁶ According to OCR staff, the strategic plan was developed over a 1-year period, beginning in 1994.¹⁵⁷ OCR staff in the regions provided input into the plan.¹⁵⁸ Each regional office held consumer outreach and customer meetings in February and March 1994. The regional offices provided headquarters OCR with summaries of those meetings.¹⁵⁹ In addition, two regional managers were on the steering committee that developed the strategic plan. Other regional managers and supervisors provided input, and

¹⁵¹ HHS, OCR, "GPRA Annual Performance Plan—FY 1999," (hereafter cited as HHS/OCR, "FY 1999 GPRA Plan"), p. 1.

¹⁵² Ronald G. Copeland, associate deputy director, Office of Program Operations, OCR, HHS, memorandum to regional managers, OCR, Regions I–X (re: FY 1998 Annual Operating Plan), pp. 1–2 (hereafter cited as OCR, FY 1998 AOP guidance).

¹⁵³ USCCR, *Federal Title VI Enforcement*, pp. 181–84. See also OPO interview, pp. 58–60 (statements of Mackey).

¹⁵⁴ Garrison and Guerrero interview, p. 2 (statement of Garrison); Cushing interview, p. 3.

¹⁵⁵ O'Brien and Mackey interview, p. 9 (statement of O'Brien). The GPRA requires that strategic plans "be updated and revised at least every three years." 5 U.S.C. § 306 (b) (1994). According to OCR, its strategic plan is being updated and has an expected completion date of August 1999. Perez letter, July 7, 1999, addendum, p. 3.

¹⁵⁶ HHS/OCR "Strategic Plan, 1994."

¹⁵⁷ OMPE interview, p. 2.

¹⁵⁸ Carter interview, p. 2; Halverson interview, p. 4.

¹⁵⁹ OMPE interview, pp. 2–3 (statement of Melov). During the customer outreach meetings, OCR customers provided input on issues with which OCR should be concerned. These issues were presented to the strategic plan steering committee and were used to develop the strategic plan. OPO interview, p. 56.

¹⁴⁵ See generally interviews with EOS in all regions. See also chap. 4.

¹⁴⁶ USCCR, *Federal Title VI Enforcement*, pp. 240–45.

¹⁴⁷ *Ibid.*, pp. 238, 246–48.

¹⁴⁸ See chap. 4.

¹⁴⁹ HHS/OCR "Strategic Plan, 1994."

¹⁵⁰ Pub. L. 103–62, 197 Stat. 285 (codified at 5 U.S.C. § 306, 31 U.S.C. §§ 1115–1119 (1994)).

regional staff commented on the plan through the union. Operating divisions also participated in the planning process.¹⁶⁰ OCR also worked with representatives from the OPDIVS to receive input.¹⁶¹ The Secretary of Health and Human Services approved the plan on January 20, 1995.¹⁶²

The strategic plan includes an analysis of the challenges facing OCR in achieving its mission, including the country's increasing diversity and the current climate of fiscal retrenchment.¹⁶³ It emphasizes the need for civil rights enforcement to "be an integral part of the deliberations on issues as diverse as health care reform, welfare reform, long-term care, adoption and child welfare, immigration, jobs, preventive health initiatives, and the location and integration of services."¹⁶⁴ The plan also lists eight "action principles" to guide OCR's implementation of the strategic plan, which, according to the plan, must be done continuously in order to implement the plan effectively:¹⁶⁵

- Seeking public input on the highest priority civil rights issues.
- Putting customers first by keeping them informed.
- Communicating effectively with the public, including persons with limited English proficiency.
- Rearranging and reinvigorating the compliance process to make it more efficient.
- Developing partnerships with other HHS offices.
- Selecting and developing employees "who share OCR's vision and will carry out its mission."
- Creating an organization that supports and encourages employee training and development.
- Empowering employees.¹⁶⁶

OCR staff think progress has been made on the eight action principles. The Region III manager

stated that the action principles gave OCR more direction than it has had in a long time.¹⁶⁷ The regional manager in Region IV stated that OCR puts customers first through its outreach activities.¹⁶⁸ The Region III manager said that complainants are their customers, and the investigators know that they have to stay in touch with the complainants.¹⁶⁹ Both managers said that OCR seeks public input through outreach.¹⁷⁰ Further, staff members in the regions stated that they effectively communicated with the public and that many of their efforts were focused on limited English proficiency.¹⁷¹

With regard to making the compliance process more efficient, the Region III manager stated that this has been accomplished in a variety of ways. For example, he stated that approximately 4 years ago OCR initiated a series of pilot programs in which the regions tried different approaches to doing investigations. Further, intake has been changed to a process in which complaints are prioritized. In addition, OCR has moved more in the direction of using alternative dispute resolution.¹⁷² However, OCR has failed to sufficiently address the final two action principles, which focus on selecting employees who share OCR's vision and creating an organization that supports and encourages employee training and development. There have been very few new hires and very little training.¹⁷³ Without additional staff and training for all staff, OCR cannot accomplish this part of its strategic plan, which is integral to strengthening its civil rights enforcement efforts.

OCR has also had mixed success in accomplishing the three long-range goals identified in the strategic plan: (1) provide leadership in the creation and evolution of a departmentwide civil rights program, (2) increase access to and participation in HHS programs through the preven-

¹⁶⁰ OMPE interview, pp. 2-3 (statement of Melov).

¹⁶¹ HHS/OCR "Strategic Plan, 1994," p. 3.

¹⁶² USCCR, *Federal Title VI Enforcement*, p. 236.

¹⁶³ HHS/OCR, "Strategic Plan, 1994," pp. 1-2.

¹⁶⁴ *Ibid.*, p. 2.

¹⁶⁵ *Ibid.*, p. 4.

¹⁶⁶ *Ibid.*

¹⁶⁷ Cushing interview, p. 3.

¹⁶⁸ Chretien interview, p. 6.

¹⁶⁹ Cushing interview, p. 4.

¹⁷⁰ Chretien interview, p. 6; Cushing interview, p. 4.

¹⁷¹ Cushing interview, pp. 3-4. See Chretien interview, p. 6; OCR Region X EOS interview, p. 3; George Bennett, Sandra Brumly, and Delores Wilson, equal opportunity specialists, Region VI, OCR, HHS, telephone interview, Feb. 2, 1999, p. 1 (hereafter cited as OCR Region VI EOS interview).

¹⁷² Cushing interview, p. 4.

¹⁷³ *Ibid.* See "Workload and Staffing," above, and "Staff Training," below.

tion or elimination of unlawful discriminatory barriers and practices, and (3) redevelop the infrastructure of OCR to facilitate execution of the HHS civil rights mission.¹⁷⁴ It appears that the most significant progress has been made in working with operating divisions on various initiatives.¹⁷⁵ OCR, however, has failed to make itself a well-known force in the agency, and, as such, has not provided leadership in the creation and evolution of a departmentwide civil rights program.¹⁷⁶ OCR remains isolated from the rest of the agency and, although it participates in several agencywide initiatives, it appears to play more of a reactive than proactive role in civil rights issues facing the agency.

To achieve its goal of increasing access to and participation in HHS programs, OCR identified title VI of the Civil Rights Act of 1964 and section 504 of the Rehabilitation Act of 1973 as "departmental priority civil rights areas." However, OCR is primarily focusing only on discrimination against minorities in access to health care programs relating to persons of limited English proficiency and discrimination against persons with HIV/AIDS.¹⁷⁷ In focusing on these issues, the strategic plan stated that OCR will conduct compliance reviews of managed care organizations, develop guidelines on standards for the provision of interpreter and translation services, issue updated title VI guidelines for hospitals and nursing homes and section 504 guidelines for nursing homes, investigate medical redlining practices, work with the Office of Women's Health and the Office of Minority Health to evaluate access to clinical preventive services for minority women, and evaluate access to renal dialysis services for persons who are HIV positive.¹⁷⁸ Unfortunately, OCR has not completely realized this goal.

To enhance operational efficiency, OCR planned to reduce case backlogs, develop teams for priority areas, redraft the *Investigative Procedures Manual*, streamline reporting for the annual operating plan, and focus resources on high-priority issues.¹⁷⁹ OCR has made some progress toward this goal. It has issued a new compliance review manual and has developed a priority system for handling complaints. However, policy development remains weak.¹⁸⁰ Under the second goal, the strategic plan also calls for working with recipient State agencies to initiate pilot projects, working with operating division and staff division representatives and their customers to monitor remedial plans and to prepare "methods for compliance," developing technical assistance programs to train State and local staff, and publishing model "methods of administration."¹⁸¹ OCR's associate deputy director for the Office for Program Operations stated that OCR has been working more closely with the operating divisions, a goal identified in the 1994 Strategic Plan.¹⁸² Although OCR staff have worked on projects with the OPDIVS, their participation remains uneven across the regions.¹⁸³ Further, regions have done little work with the States in regards to methods of administration.¹⁸⁴

The final goal identified by the strategic plan involves redeveloping the infrastructure of OCR. To achieve this goal, OCR planned to train its staff to ensure that they have the skills they need and to develop sources for outside consultants. In addition, OCR planned to "develop a culture that promotes the exercise of leadership at all levels of the organization and rewards conduct consistent with OCR's values."¹⁸⁵ This appears to have been a low priority, as little progress on this goal has been made. Staff receive minimal training aside from on-the-job training, and formal training plans have not been developed.¹⁸⁶

¹⁷⁴ HHS/OCR, "Strategic Plan, 1994," p. 6.

¹⁷⁵ See OCR interview, July 29, 1998, p. 3 (statements of Copeland); O'Brien and Mackey interview, pp. 8-9 (statements of Mackey and O'Brien). Several regional staff also discuss joint programs with the OPDIVS. OCR Region IV EOS interview, p. 3; OCR Region VI EOS interview, p. 3; OCR Region VIII EOS interview, p. 8; OCR Region I EOS interview, p. 6.

¹⁷⁶ Gordon Bonnyman, managing attorney, Tennessee Justice Center, Nashville, TN, telephone interview, Feb. 4, 1999, p. 6.

¹⁷⁷ HHS/OCR, "Strategic Plan, 1994," p. 11.

¹⁷⁸ *Ibid.*, p. 12.

¹⁷⁹ *Ibid.*, pp. 14-15.

¹⁸⁰ See chaps. 3 and 4.

¹⁸¹ HHS/OCR, "Strategic Plan, 1994," pp. 15-16.

¹⁸² OCR interview, July 29, 1998, p. 3 (statements of Copeland).

¹⁸³ See chap. 5.

¹⁸⁴ See chap. 4.

¹⁸⁵ HHS/OCR, "Strategic Plan, 1994," pp. 18-19.

¹⁸⁶ See "Staff Training," below.

HHS Strategic Plan

OCR staff stated they did not know if the HHS departmental strategic plan included civil rights goals.¹⁸⁷ They also noted that the OCR plan was developed before the Department's plan was developed and that the OCR plan is "probably" incorporated into the Department's plan by reference.¹⁸⁸ The strategic plan for the Department is separate from OCR's strategic plan, and was issued in 1997. Although the HHS plan does not specifically identify civil rights as one of its primary goals, one of the six goals established by the plan is to "[i]mprove access to health services and ensure the integrity of the nation's health entitlement and safety net programs."¹⁸⁹

However, the HHS strategic plan fails to fully address gender, racial, and ethnic differences in access to health care services, health care financing, and health research. OCR is specifically mentioned in the context of adoption and foster care, health services for the elderly, community-based and home health care, and medicaid and medicare. However, OCR's enforcement activities and its role in initiatives to eliminate disparities in health status are not clearly defined. In addition, the HHS strategic plan provides little insight as to how the goal of improving access to health care, as well as the other goals, will be accomplished.

Overall, the HHS strategic plan is inadequate. Further, civil rights enforcement at HHS lacks effective leadership and direction. The HHS strategic plan demonstrates that civil rights is neither a top priority nor an integral part of HHS' primary strategic planning.

Government Performance and Results Act Annual Performance Plans

HHS follows a decentralized approach for implementing the Government Performance and Results Act.¹⁹⁰ Thus, OPDIVS and individual

programs "have significant responsibility for transitioning HHS to full compliance with GPRA."¹⁹¹ As such, OPDIVS and other offices, such as OCR, have individual GPRA performance plans. The departmental GPRA performance plan is stated in terms of performance measures and links to the budget. Civil rights goals are not included as part of the departmental plan.¹⁹² Generally, OCR's FY 1999 GPRA Annual Performance Plan meets the requirements of the GPRA. The FY 1999 Annual Performance Plan flows from OCR's strategic plan; the five performance objectives in the GPRA annual performance plan are directly related to the strategic plan's goals and objectives.¹⁹³ The GPRA annual performance plan addresses reducing discrimination in high-incidence and high-priority areas, using partnerships to assist OCR in carrying out its mission, and enhancing OCR's operational efficiency.¹⁹⁴ The performance objectives identified in OCR's GPRA plan include the high-priority issues identified during the strategic planning process: adoption and foster care, managed care, services for limited-English-proficient persons, and welfare reform.¹⁹⁵ In addition, the fifth performance objective deals with increasing operational efficiency by focusing resources on high-priority areas.¹⁹⁶ The performance objectives are:

objectives, an explanation of how performance goals are related to the strategic plan, a discussion of external factors that could affect the achievement of the goals and objectives, and a description of how program evaluations are to be used in establishing or revising the goals and objectives. 5 U.S.C. § 306 (1994).

¹⁹¹ HHS, Office of Finance, "GPRA Overview," accessed at <<http://www.hhs.gov/progorg/fin/overview.html>>.

¹⁹² HHS, *1996-2000 CFO 5 Year Plan*, accessed at <<http://www.hhs.gov/progorg/fin/intro.html>>.

¹⁹³ HHS/OCR, "FY 1999 GPRA Plan," p. 1. OCR's 1994 Strategic Plan included three goals: (1) taking the lead in creating a departmentwide civil rights program, (2) increasing access to and participation in HHS programs, and (3) redeveloping OCR's infrastructure. *Ibid.*

¹⁹⁴ *Ibid.*

¹⁹⁵ *Ibid.* The four high priority areas were identified during OCR's strategic planning process through public forums with advocacy and other community-based organizations, and ongoing OCR compliance activities that identified key issues where OCR should focus its resources. *Ibid.* See also OCR interview, July 29, 1998, p. 4 (statement of Malester).

¹⁹⁶ HHS/OCR, "FY 1999 GPRA Plan," p. 1.

¹⁸⁷ Garrison and Guerrero interview, p. 3 (statement of Garrison).

¹⁸⁸ *Ibid.* (statements of Guerrero and Garrison).

¹⁸⁹ HHS, "Strategic Plan, 1997" accessed at <<http://aspe.os.dhhs.gov/hhsplan/intro.htm>> p. 3 (hereafter cited as HHS, "Strategic Plan, 1997").

¹⁹⁰ The GPRA requires Federal agencies to develop a strategic plan and annual performance plans that include the following items: a mission statement, general goals and objectives, a description of how to accomplish the goals and

- Increase the number of HHS adoption/foster care service providers who provide nondiscriminatory placements for children.
- Increase access for minorities and persons with disabilities to nondiscriminatory services in managed care plan settings.
- Increase access to HHS services for limited-English-proficient persons.
- Increase the number of State and local welfare agencies and service providers administering Temporary Assistance to Needy Families (TANF) programs that are in compliance with title VI, section 504, and the ADA.
- Increase the percentage of resources focused on high-priority issues.¹⁹⁷

To implement the four high-priority areas in the GPRA plan, OCR plans to build on joint initiatives with OPDIVS, as they implement new initiatives and improve ongoing programs.¹⁹⁸ Through consultations, technical assistance, and other outreach activities, OCR plans to educate State and local agencies, service providers, and advocacy and other community-based organizations to ensure that civil rights requirements are being enforced.¹⁹⁹

During FY 1998, OCR planned to focus its compliance review and outreach and education activities on the performance objectives' four high-priority areas. During FY 1999, OCR will use both outputs and outcomes to measure performance. During the fiscal year, OCR plans to develop performance measures relative to compliance, as well as develop a system for collecting data before and after compliance reviews and complaint investigations over a 2- to 3-year period to show the effect on beneficiaries of actions taken by HHS service providers as a result of OCR's initiatives.²⁰⁰ With respect to performance measures for the four priority areas (adoption and foster care, managed care, services for limited-English-proficient persons, and welfare reform), OCR will use the following output measures: increased number of reviews conducted, increased number of corrective actions and no violation findings from review and complaint

investigation activities, increased number of consultations/technical assistance provided, increased number of partnerships established, and increased number of outreach activities conducted.²⁰¹

With respect to outcome-oriented measures for collecting complaints data, OCR plans to collect data regarding access to services received prior to the initiation of a review (or during the review/investigation if preexisting data are unavailable) and after the review. The collection of "pre-OCR and post-OCR involvement data" is the means by which the office will validate if the work being done provides the expected effect on the beneficiaries. The period for which OCR will require a provider to submit data will depend on the size of the facility and/or the types and number of services for which the facility will be collecting data.²⁰² For example, to determine if OCR's work has achieved the desired result, OCR will require recipients that have been investigated to submit data after they have been reviewed.²⁰³ This information will be entered into the Case Activity Tracking System (CATS).²⁰⁴ Once this data collection process has been fully implemented, OCR plans to aggregate data and establish goals for its activities, such as managed care, limited English proficiency, adoption, and title VI activities.²⁰⁵

However, OCR appears confused about the purpose of the GPRA. In a recent letter to a hospital that OCR had investigated, OCR identified the postreview data that the recipient would need to submit to OCR by July 31, 1999.²⁰⁶ OCR cites the GPRA as its authority for collecting the data.²⁰⁷ However, the title VI regulations are the appropriate authority for data collection. In fact, the Region IX manager stated that the GPRA does not give agencies the authority to require data from recipients, nor did it intend for agen-

²⁰¹ Ibid.

²⁰² Ibid. See also OMPE interview, p. 6 (statement of Melov).

²⁰³ OMPE interview, p. 7 (statement of Melov).

²⁰⁴ OCR, *CATS Procedures Manual*, chap. VII.

²⁰⁵ OMPE interview, p. 7 (statement of Melov).

²⁰⁶ Ralph D. Rouse, Jr., regional manager, OCR, HHS, letter to Don Bowen, superintendent, Griffin Memorial Hospital, Norman, OK (ref: 06987038), pp. 3-4 (hereafter cited as Rouse letter, 1998).

²⁰⁷ Rouse letter, 1998, p. 3.

¹⁹⁷ Ibid., pp. 5-8.

¹⁹⁸ Ibid., p. 1.

¹⁹⁹ Ibid.

²⁰⁰ Ibid., p. 2.

cies to use it as an authority to collect data.²⁰⁸ Further, in 1998 OCR acknowledged its difficulty in implementing the GPRA. According to a memorandum from the acting director of OCR at that time:

There are a number of definitional and data problems that have arisen with our GPRA implementation. We have discovered that some Regional Offices have not begun to collect the data because of continuing confusion about the process. We have also found a number of the states with which we do not yet have a common understanding on the data to be collected. There is also more work to be done with some OPDIV partners to reach agreement on the data we seek.²⁰⁹

Although OCR stated at that time that it was working on resolving the problems related to GPRA data collection,²¹⁰ it appears that confusion concerning GPRA requirements persists.

Annual Operating Plans

Headquarters initiatives are specified in the annual operating plan.²¹¹ A careful process of planning is coordinated with the regional offices. OCR regional managers present plans to headquarters OCR which has the opportunity to comment on them.²¹² Annual operating plans and the strategic plan required under the Government Performance and Results Act are tied together.²¹³

Headquarters OCR provides guidance to the regions for developing their annual operating plans.²¹⁴ OPO staff noted that the AOP guidance is essentially for activities other than complaints. The guidance contains the national priorities that the director has decided are important. Regional offices can select the issues they want to address in fashioning their compliance review and outreach plans for the upcoming year.²¹⁵ However, regional staff are required to do reviews in certain areas. For example, in the

year that the Multiethnic Placement Act²¹⁶ was enacted and effective, headquarters mandated that the regional offices conduct compliance reviews in their States to ascertain compliance with that law. Other issue areas, such as managed care and redlining, have been included on the list of priorities.²¹⁷ However, OPO staff noted that if such issues were not relevant in certain regions, or if other more important or new issues arise regions are free to look at other issues. OPO staff noted that the regions use several methods to determine the issue areas that they will address.²¹⁸

For FY 1998, headquarters identified nine programmatic priorities to be included in the regions' annual operating plans:

- Adoption and foster care.
- Limited English proficiency.
- Managed care.
- Temporary assistance to needy families.
- Hospital services.
- Other health care and social services delivery systems.
- Presidential/Secretarial initiatives on race.
- Departmental initiative on adult immunization and vaccine safety.
- Title IV/title IX applied to federally conducted programs.²¹⁹

The first four priorities are identified in the annual GPRA Performance Plan and the strategic plan. The remaining priorities stem from the strategic plan and Presidential and Secretarial initiatives.²²⁰ In developing their AOPs, the regions are encouraged to include regional priorities as well. Regional priorities are developed from outreach activities, complaints, investigations, media reports, and various other sources of information.²²¹

However, the annual operating plans are unwieldy compendiums of reporting forms that specify investigation, review, and outreach proj-

²⁰⁸ Pollack interview, p. 10.

²⁰⁹ Garrison memo, p. 5.

²¹⁰ *Ibid.*

²¹¹ Garrison and Guerrero interview, p. 2 (statement of Garrison).

²¹² *Ibid.*

²¹³ *Ibid.*

²¹⁴ Carter interview, p. 2.

²¹⁵ OPO interview, p. 30.

²¹⁶ Pub. L. No. 103-382, 108 Stat. 3518 (codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997)).

²¹⁷ *Ibid.*

²¹⁸ *Ibid.*

²¹⁹ OCR, FY 1998 AOP guidance, p. 1.

²²⁰ *Ibid.*, p. 2.

²²¹ Carter interview, p. 3.

ects. For example, the plans for Region I comprise over 100 pages of reporting forms.²²² Although it appears as if great effort is put into creating these reports, little information is provided as to why certain issues or locations were targeted for outreach or investigation, other than a general reference to the director's or Secretary's priorities.

In the annual operating plans, OCR does not address crucial issues such as quality of care; the effect of structural changes (such as changes in Medicare and HMOs); and racial, ethnic, and gender disparities in medical procedures. Many of the investigation, review, and outreach efforts identified in the FY 1998 Annual Operating Plans focus on limited English proficiency (LEP), the Americans with Disabilities Act, and section 504 of the Rehabilitation Act.²²³ In addition, while many of the projects look at whether there are disproportional services to minorities based on statistical analyses, it is not clear if OCR performs an in-depth analysis of the quality of care given to minorities (including types of medical procedures, attention and attitudes of facility staff, and physical environment) to determine if it is equivalent to the care given to nonminorities.

For example, the FY 1998 Annual Operating Plan for Region IV includes 23 projects covering the following areas: Temporary Assistance for Needy Families, managed care, Hill-Burton issues related to the provision of hospital services, adoption and foster care, and limited English proficiency. In addition, the region planned activities related to the Secretarial Initiative on Adult Immunization and Vaccine Safety, a review of the Children's Health Insurance Programs, title VI training for State agencies, and recruitment of student interns for the historically black colleges and universities initiative.²²⁴ Several of the projects appear to be identical. For example, the Hill-Burton reviews are described as follows:

ISSUES: Whether or not the recipient has developed and implemented policies and procedures to ensure that persons residing in its service [area] are not de-

nied treatment, service and/or admission to its facility on the basis of race.

REASON FOR SELECTION OF THIS FACILITY: Information in the CSAR [Community Service Assurance Report] and/or the Title VI Survey Results indicate that in its service to the Black population, this facility has a disproportion between Inpatient Data and Census Data. Based on this information, OCR will seek to determine whether or not a compliance problem exists.²²⁵

Such standard statements with little description fail to provide sufficient detail as to how the regional staff will conduct these reviews. There is little description of expectations, methodologies, and planned outcomes of the projects in most of the annual operating plans. For instance, for several of its projects, the operating plan for Region III states that it will examine the issue of "[w]hether persons are denied or receive less than equal services on the basis of their race and national origin."²²⁶ However, the plan provides no details of how this will be accomplished.²²⁷ Similarly, Region V planned a special outreach project on nursing homes that involved the following steps: (1) draft request for legal guidance, (2) identify homes, (3) contact homes after receipt of guidance.²²⁸ The plan provides this brief description: "Obtain decision as to whether restrictions violate Age Discrim[ination] Act. If so, obtain changes in admission policy from homes."²²⁹ It is not clear what particular steps will be taken to obtain compliance with the Age Discrimination Act.

The description of similar reviews (e.g., title VI review of hospitals) is precisely the same, providing little indication of what will occur in the review. For example, Region II submitted 32

²²⁵ Ibid.

²²⁶ HHS, OCR, Region III, FY 1998 Annual Operating Plan.

²²⁷ According to OCR, these documents are not meant to describe the ways reviews are to be conducted. They are flexible workplans that describe generally what a region plans to do. An Investigative Plan would give the specific details of a review or an investigation. OCR, "Comments," p. 1. Nonetheless, annual plans, investigative plans, the strategic plan, and other planning documents do not appear to be integrated fully with one another.

²²⁸ HHS, OCR, Region V, FY 1998 Annual Operating Plan (hereafter cited as OCR, Region V, FY 1998 AOP).

²²⁹ Ibid.

²²² HHS, OCR, Region I, FY 1998 Annual Operating Plan (hereafter cited as OCR, Region I, FY 1998 AOP).

²²³ See, e.g., OCR, Region I, FY 1998 AOP.

²²⁴ HHS, OCR, Region IV, FY 1998 Annual Operating Plan.

pages of descriptions of limited-scope compliance reviews with precisely the same description:

(1) Whether the facility's established policies and/or procedures results in different treatment, denials or delays, in the provision of medical services to LEP persons. (2) Whether the facility's established policies and/or procedures results in different treatment, denials or delays, in the provision of medical services [to those] who are hard of hearing. (3) Whether the facility has established policies and procedures for the provision of interpreter services for both groups (LEP and deaf/hard of hearing).²³⁰

This approach fails to acknowledge demographic and regional variations that are taken into account when planning such reviews. It also suggests a lack of careful planning and analysis of the issues and the areas in which the facilities are located.

Further, regional activities seem to overlap, yet there is no mention of coordination among regions. For example, the Region I describes an investigation project as follows:

OCR will initiate an investigation to determine whether the doctor and hospital discriminated against a patient on the basis of her HIV status. This project will involve sending correspondence to the doctor and interviews. It will result in making sure the hospital is aware of its obligations in regards to discrimination against persons with HIV/AIDS. It will also guarantee that other HIV/AIDS patients are not denied care.²³¹

However, Region VI described several projects with a similar issue: "whether persons with HIV/AIDS are admitted to the nursing home in compliance with section 504 of the Rehabilitation Act of 1973."²³² In both of these examples, it is unclear how the objectives of the review will be accomplished, nor it is clear how discrimination will be eliminated. In addition, the disparity in the information provided presents difficulties in monitoring regional activities and comparing activities from one region to another.

It also is unclear from the annual operating plans whether regions are coordinating other

activities, or if they are duplicating efforts. For example, Region II planned an asian outreach project for FY 1998 in which staff were to "develop a fact sheet on removing barriers to health care for Asians" and to "prepare standardized information and technical assistance package for recipients addressing needs of Asian American beneficiaries."²³³ Similarly, the asian outreach project for Region I involves "develop[ing] an instrument to receive [and] process civil rights issues from appropriate bodies of city, State [and] Federal governments."²³⁴ These overlapping and complimentary activities should be coordinated through OCR so that efforts are not duplicated.

In addition, plans do not clearly show the effect of planned activities on staff and resources. Although travel costs and staff hours are provided for many of the projects, the effect of these figures is not discussed. The lack of specificity and clarity in the description of plans, goals, and resources, and the poor organization of the plans, results in annual operating plans that appear inefficient. It is not clear how these plans can be used effectively. Further, the plans do not have enough substance to assess their efficiency from civil rights, programmatic, or budgetary standpoints.

Finally, the regional offices do not appear to use consistent planning methods. For example, Region X identifies several facilities in which it will do compliance reviews, yet the issues were "not determined yet."²³⁵ However, Region V identified issues to be reviewed, yet had not yet determined which facilities would be reviewed.²³⁶ These discrepancies among planning techniques and projects conducted could result in uneven implementation of civil rights statutes, policies, and regulations throughout the country.²³⁷

²³³ HHS, OCR, Region II, FY 1998 Annual Operating Plan.

²³⁴ OCR, Region I, FY 1998 AOP.

²³⁵ HHS, OCR, Region X, FY 1998 Annual Operating Plan.

²³⁶ OCR, Region V, FY 1998 AOP.

²³⁷ In August 1998, OCR acknowledged several of the deficiencies in its annual operating plans. Before FY 1999, the AOP had not been in place at the start of the fiscal year, "thereby creating management problems for regional managers and their staff." Garrison memo, p. 4. The annual operating plans also duplicated other reporting procedures. OCR stated that the FY 1999 AOP "otherwise promises to streamline OCR operations." *Ibid.*, p. 5.

²³⁰ HHS, OCR, Region II, FY 1998 Annual Operating Plan (hereafter cited as OCR, Region II, FY 1998 AOP).

²³¹ OCR, Region I, FY 1998 AOP.

²³² HHS, OCR, Region VI, FY 1998 Annual Operating Plan, pp. 7-25.

Annual Civil Rights Implementation Plans

Executive Order 12250²³⁸ requires the Attorney General to evaluate periodically the implementation of civil rights provisions covered by the order. To fulfill this obligation, the Department of Justice (DOJ), Coordination and Review Section relies on the submission and review of agencies' Civil Rights Implementation Plans.²³⁹ The basic framework for the Civil Rights Implementation Plans has not changed since its development in 1981. According to the director of Program and Compliance, all agencies' Civil Rights Implementation Plans should include and discuss the same criteria, but each agency has flexibility in plan format and presentation.

In its 1996 report on title VI, the Commission reviewed the HHS Civil Rights Implementation Plans for 1989 to 1993.²⁴⁰ In general, the plans did not fulfill the purposes for which they were designed by DOJ.²⁴¹ Specifically, the long-range goals and major and short-term objectives set forth in the 1990 plan follow the format provided by the DOJ for agencies' implementation plans. However, they are not as detailed and do not specify multiyear strategies for achieving long-range goals and major objectives, as in DOJ's example.²⁴² The lack of specificity made it difficult to determine whether HHS was achieving its title VI goals and objectives. Beyond a general statement of its expected staff and budget for the year, the 1990 plan contained no information on how OCR intended to use its resources to accomplish its goals and objectives. Furthermore, there is no indication that the goals and objectives are based upon the level of

expected staff and resources during the budgetary planning cycle at HHS.²⁴³

OCR's FY 1996 annual civil rights implementation plan contains many of the deficiencies the Commission identified in the 1990 plan. OCR provided much documentation to DOJ, yet provided little explanation. In response to the requirement to describe the relationship between OCR's goals and resources, OCR merely provided a copy of OCR's 1994 Strategic Plan and its FY 1997 congressional budget justification.²⁴⁴ To describe its civil rights organization and staffing for the enforcement of civil rights statutes, HHS referred DOJ again to the 1994 Strategic Plan, provided the FY 1998 budget justification, and provided an organization chart.²⁴⁵ However, OCR did not provide an explanation of the attached documents, nor did it describe how staffing and budget affect its civil rights enforcement efforts.

According to the deputy to the associate director for the Office of Program Operations, each annual implementation plan is an update to information provided in a previous year.²⁴⁶ For example, the 1998 annual implementation plan provided to the Commission provides only summaries of significant cases.²⁴⁷ This is unacceptable as an implementation plan. The Commission identified this as a deficiency in 1995, stating:

In general, HHS' Civil Rights Implementation Plans do not serve as an OCR management tool, as intended by the Department of Justice. In particular, they fail to identify specific goals and objectives and the relationship between available and future staff, resources, and workload and the accomplishment of such goals and objectives. Overall, the plans do not provide sufficient information for the Department of Justice to evaluate HHS' Title VI enforcement program.²⁴⁸

²³⁸ 3 C.F.R. 298 (1981), *reprinted in* 42 U.S.C. § 2000d-1 (1994).

²³⁹ See USCCR, *Federal Title VI Enforcement*, pp. 89-98, for a detailed discussion of civil rights implementation plans and requirements.

²⁴⁰ See USCCR, *Federal Title VI Enforcement*, p. 235. HHS/OCR staff refer to these plans as the annual implementation plans (AIP). See OPO interview, pp. 58-60.

²⁴¹ See USCCR, *Federal Title VI Enforcement*, chaps. 3 and 4, for discussions of the Department of Justice's purpose in requiring civil rights implementation plans.

²⁴² *Ibid.*, p. 235. The example given by the Department of Justice for a long-range goal is "To eliminate backlogged civil rights complaints (i.e., carried over 1980 days with no action)." The accompanying major objective gives a timeframe: "Close 90 percent of all simple and 50 percent of all complex backlogged cases by the end of fiscal year 1983." The short-term objectives in the example are meant to be carried out over several fiscal years. *Ibid.*, pp. 92-93.

²⁴³ *Ibid.*, p. 235.

²⁴⁴ HHS, OCR, "FY 96 Annual Implementation Plan" (hereafter cited as OCR, "FY 96 Annual Implementation Plan"). The copy of OCR's implementation plan provided to the Commission did not include the attached budget justifications.

²⁴⁵ OCR, "FY 96 Annual Implementation Plan."

²⁴⁶ OPO interview, p. 60 (statement of Mackey).

²⁴⁷ HHS, OCR, "Significant Cases, Annual Implementation Plan," FY 1998 (hereafter cited as OCR, "FY 98 Annual Implementation Plan").

²⁴⁸ USCCR, *Federal Title VI Enforcement*, p. 249.

Merely attaching documents and referring to them does not provide insight into the goals of the agency and progress in meeting those goals. There is no explanation of the relevance of the significant case summaries or the budget requests in the strategic plan. Further, because the strategic plan is rather outdated and has no explanation of whether or not its goals have been accomplished, the annual implementation plan is rendered useless as both a management tool and a way to assess the success of title VI enforcement efforts.

Initiatives on Health Care for Women and Minorities

According to the director of the Policy and Special Projects Staff, every component of the Department is working on initiatives related to inequities in health care, and OCR is an active part of those groups within HHS working on such issues.²⁴⁹ Members of OCR staff are on task forces and steering committees implementing initiatives such as the Hispanic Agenda for Action, listening sessions with Native Americans, an initiative relating to historically black colleges and universities, and a culture competency initiative.²⁵⁰ In addition, OCR is in the early stages of an initiative on disparities in quality of health care for racial and ethnic minorities in conjunction with the OPDIVS and the Office of the Assistant Secretary for Planning and Evaluation.²⁵¹ Many of these initiatives stem from the Secretary's Departmental Minorities Initiatives program.²⁵² The OCR Minority Initiatives Coordinating Committee is charged with developing a minority initiatives plan that will consolidate the Department's minority issues. Several regions included information on their activities in relation to the OCR Minority Initiatives Coordinating Committee in their annual operating plans. For example, Region VIII noted that the regional civil rights attorney is a member of the committee and serves on the subcommittee responsible for developing the plan.²⁵³

²⁴⁹ PSPS interview, p. 12. See also OPO interview, pp. 16–17 (statement of Mackey).

²⁵⁰ O'Brien and Mackey interview, p. 9 (statement of Mackey).

²⁵¹ Ibid.

²⁵² These initiatives are discussed in USCCR, *The Health Care Challenge*, vol. I, chap. 4.

²⁵³ HHS, OCR, Region VIII, FY 1998 Annual Operating Plan.

The new director of OCR recognizes the need for OCR to be more involved in addressing disparities in health care. One of his goals is to raise the profile of OCR both within the Department and externally.²⁵⁴ The director stated that OCR needs to be "at the head of the pack doing aggressive enforcement."²⁵⁵

In July 1999, OCR provided the Commission with the following information on its new initiatives.²⁵⁶ According to OCR, the agency strongly supports the Department's Initiative to Eliminate Racial Disparities, and regularly communicates with other HHS components that are involved in this initiative. OCR states that it has taken a number of aggressive steps to support this initiative. It has established a Racial Disparities Task Force, which will coordinate the development and implementation of a comprehensive OCR strategy for attacking racial disparities. This task force will analyze data on medical procedures, conduct compliance reviews, and conduct outreach to communities.²⁵⁷ Initially, the task force will concentrate on New York State, for which information on specific instances of disparities in health care is available.²⁵⁸ Using title VI, it will seek to ensure that people of color have meaningful access to quality health care.²⁵⁹

The director of OCR stated OCR also will undertake an initiative on redlining in the home health and managed care contexts. In the home health context, OCR is concerned that some home health agencies may be refusing to provide service in certain, predominantly minority sections of town. In the managed care setting, OCR will examine how managed care plans establish their service areas, and whether they are deliberately bypassing communities of color in their marketing practices.²⁶⁰ Further, at OCR's recent regional managers conference, experts from the U.S. Department of Housing and Urban Development and the U.S. Department of Justice provided training on how to conduct a redlining in-

²⁵⁴ Perez interview, pp. 3–4.

²⁵⁵ Ibid., p. 4.

²⁵⁶ Perez letter, July 7, 1999, pp. 2–5.

²⁵⁷ Ibid., pp. 3–4.

²⁵⁸ Ibid., p. 4. See chap. 3, for a discussion of the racial disparities in health care uncovered by *Newsday*.

²⁵⁹ Perez letter, July 7, 1999, p. 2.

²⁶⁰ Ibid., p. 3.

vestigation.²⁶¹ Employees will receive additional training on redlining by the end of FY 1999.²⁶²

In addition, OCR has stated that it recognizes the need to issue formal, published guidance clarifying the obligations of health and human service providers in ensuring that limited-English-proficient persons have meaningful access to HHS-funded programs. Accordingly, OCR has established an LEP task force that is working with other HHS components to build consensus around this issue and compiling promising practices of providers to assist in technical assistance efforts. The LEP task force will also determine which type of published guidance (i.e., regulation, guideline, or policy) the Department will ultimately develop.²⁶³

According to OCR, the agency will undertake two significant initiatives on the Temporary Assistance to Needy Families (TANF) program in the second half of 1999.²⁶⁴ First, OCR informed the Commission that its welfare reform civil rights guidance is in the final approval cycle. It is currently being reviewed a second time at the Domestic Policy Council. Second, OCR will increase its enforcement activities in the TANF area. For example, the regional office in San Francisco is beginning TANF reviews of three counties in California. Among other things, the reviews will focus on: (1) whether individuals who are limited English proficient are facing discriminatory barriers, and (2) whether minorities are being improperly steered to less desirable jobs. Because the TANF program in California is a county-driven program, OCR will review all 58 counties to determine compliance.²⁶⁵

Finally, with regard to other management improvements and plans, OCR has informed the Commission that it is in the process of identifying structural and system reforms that will enhance OCR's efficiency and effectiveness.²⁶⁶ OCR indicated some of the problems it currently is confronting in meeting this objective. For example, OCR observed that the 1993 departmental review of the agency contained a number of recommendations for organizational reform of OCR

that have not been implemented. Moreover, the current OCR organizational structure was put into place in 1986, when OCR was considerably larger. Therefore, according to OCR, the current organizational structure at headquarters does not reflect today's downsized reality, and the agency recognizes that it must address this issue "promptly, appropriately and carefully."²⁶⁷

Along these lines, OCR has begun in 1999 to implement a number of useful changes to improve efficiency and productivity and increase morale.²⁶⁸ For instance, OCR now holds a monthly "all staff meeting" for headquarters staff and quarterly "all hands meetings" including staff in all 10 regional offices via telephone to encourage consistent communication across the agency.²⁶⁹

OCR Resources for Civil Rights Enforcement

Budget

Because of its severely limited budget, OCR and HHS must be creative in the distribution of its resources to ensure effective civil rights enforcement operations. OCR must establish a consistent and sustained approach to accomplishing fund increases, such as achieving a redistribution of departmental funds to OCR.

"Management-by-attrition has been necessarily accompanied by a near total lack of operating funds for staff development/training, travel, and upgraded equipment. In the regions, most travel has been curtailed for a number of years, forcing investigations to be done primarily as desk audits."²⁷⁰

OCR operates under severe budgetary constraints. According to the special assistant to the director of OCR, OCR's responsibilities and workload have increased over the past several years, yet its funding and staffing have decreased.²⁷¹ OCR's budget has fluctuated around \$20 million since 1981,²⁷² and has not kept up

²⁶¹ Ibid.

²⁶² Ibid.

²⁶³ Ibid.

²⁶⁴ Ibid., p. 4.

²⁶⁵ Ibid.

²⁶⁶ Ibid.

²⁶⁷ Ibid.

²⁶⁸ Ibid.

²⁶⁹ Ibid.

²⁷⁰ Garrison memo, p. 3.

²⁷¹ O'Brien and Mackey interview, p. 9 (statement of O'Brien).

²⁷² OCR, "Budget and FTE Usage History."

with inflation. Factoring in inflation, the FY 1999 budget of \$20.6 million is approximately 65 percent of the FY 1981 budget (see figure 2.3).²⁷³ However, other than stating that its responsibilities have increased, OCR has failed to provide documented evidence for the need to increase its budget, and a detailed action plan of how additional funds would be beneficial, which may be a cause of its static budget appropriation over the years.²⁷⁴

Almost all the regional offices stated that the lack of resources has placed them at a disadvantage, making it difficult for them to accomplish their mission.²⁷⁵ For example, staff members in Region II stated that the lack of resources has made it difficult for them to reach all of the areas covered by their region.²⁷⁶ Further, Region II lacks funds for outreach activities and publications.²⁷⁷ These limitations are relevant for all of the regions.

The FY 1999 budget supports a compliance program that focuses on: (1) implementing the adoption and foster care nondiscrimination provisions of the Small Business Job Protection Act of 1996, (2) ensuring nondiscrimination in the Temporary Assistance to Needy Families program, and (3) supporting quality health care access for racial and national origin minorities and persons with disabilities to managed care plan services, children's health programs, HIV/AIDS services, and home health care services.²⁷⁸ However, the budget fails to include a formalized system for developing policy guidance, comprehen-

sive full-scope civil rights activities, and training for the staff.

Staff noted that OCR does not have a system for monitoring and tracking expenditures on each type of civil rights enforcement activity, such as complaint investigations, preaward reviews, postaward reviews, staff training, and technical assistance.²⁷⁹ HHS has no plans for developing such a system because, from an HHS accounting perspective, this cannot be done. OCR can only infer from the casework how much time and money were spent on specific activities.²⁸⁰ The regions also do not have separate tracking systems, although they provide occasional reports to headquarters on their activities.²⁸¹ Without a tracking system, OCR headquarters and the regions cannot adequately track how their resources are spent. Such information is needed for management and planning purposes as well as for performance measures.

The FY 2000 budget request is for \$22 million. The budget request covers an "enhanced" compliance program that focuses on the same programs identified in the FY 1999 budget request (adoption and foster care, TANF programs, managed care, children's health programs, HIV/AIDS services, and home health care services).²⁸² HHS Secretary Donna Shalala noted, in her statements during the press conference in which she announced the proposed budget, that "too many of our citizens face a higher risk of illness and death" because of their race or ethnicity.²⁸³ However, to remedy this, the budget allocated \$5 billion to "health education, prevention and treatment services specifically targeted to minority Americans," which includes \$145 million for the departmental racial health disparities initiative.²⁸⁴ None of the \$5 billion

²⁷³ Ibid.

²⁷⁴ OMPE staff stated that OCR has used several strategies to enhance its budget, such as changing its presentation both within the Department and to OMB and Congress, to incorporate examples of actual cases, outreach initiatives, and activities focusing on real people, and the affect their activities have on people. In other words, OCR has attempted to "put a human face" on dry numbers to convince both the internal and external appropriators that they have a real effect on people's lives. He stated that this strategy has worked internally. OMPE interview, p. 2 (statement of Melov).

²⁷⁵ Ralph Rouse, regional manager, Region VI, OCR, HHS, telephone interview, Feb. 2, 1999, p. 2 (hereafter cited as Rouse interview); Carter interview, p. 3; OCR Region VI EOS interview, p. 4; Kyle-Holmes interview, p. 8.

²⁷⁶ Carter interview, p. 5; OCR Region II EOS interview, p. 5.

²⁷⁷ OCR Region II EOS interview, p. 7.

²⁷⁸ HHS, "FY 1999 Budget," p. 83 (OCR), accessed at <<http://www.hhs.gov/progorg/asmb/budget/fy99budget/pdf/files/1999pr.pdf>>.

²⁷⁹ OMPE interview, p. 2 (statement of Melov).

²⁸⁰ Ibid. Mr. Melov noted that to maintain data in this manner, a parallel accounting system would have to be developed within OCR. This would require staff or contractor expertise in design, development, and maintenance of the system—resources OCR does not have. Thus, it would not be worthwhile for OCR to develop such a system. Ibid.

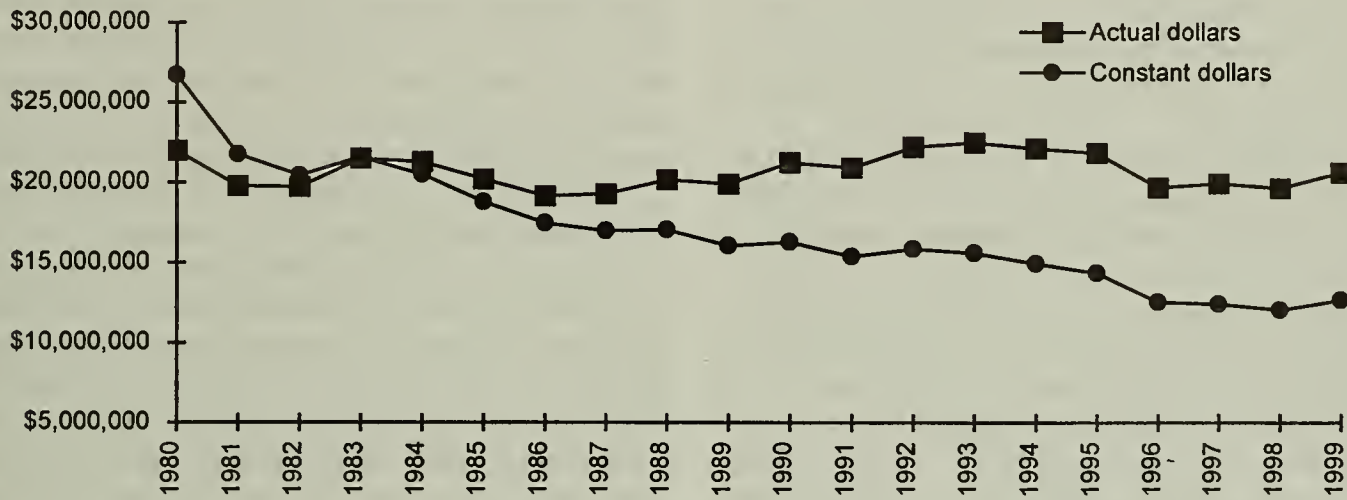
²⁸¹ Chretien interview, p. 3; Rouse interview, p. 3; Carter interview, pp. 3–4.

²⁸² HHS, "Fiscal Year 2000 Budget," Feb. 1, 1999, p. 96 (OCR).

²⁸³ Donna E. Shalala, Secretary, HHS, Remarks at the Fiscal Year 2000 Budget Press Conference, Washington, DC, Feb. 1, 1999, p. 3.

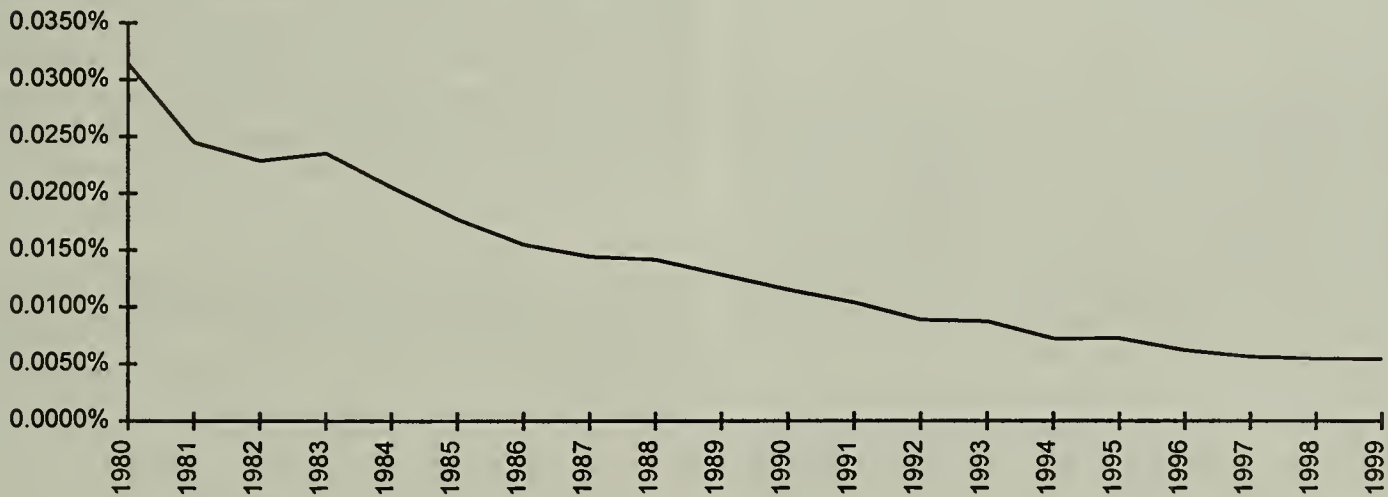
²⁸⁴ Ibid., p. 4.

Figure 2.3
OCR Budget, 1980–1990



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, "OCR Budget and FTE Usage History, FY 80 - FY 99 est.," Oct. 5, 1998. The budget was adjusted for inflation using the Consumer Price Index for All Urban Consumers (CPI-U), which is widely used as a price deflator. Roy H. Webb and Rob Willemse, "Microeconomic Price Indexes," accessed at <<http://www.rich.frb.org/macro/price.html>>. See also U.S. Department of Labor, Bureau of Labor Statistics, *BLS Handbook of Methods*, chap. 17, accessed at <<http://www.bls.gov/opub/hom/homch17%Fe.htm>>. The base years for the data are 1982-1984. U.S. Department of Labor, Bureau of Labor Statistics, "Consumer Price Index, All Urban Consumers (CPI-U), U.S. City Average," accessed at <[ftp://ftp.bls.gov/pub/special.requests/cpi/cpi.ai.txt](http://ftp.bls.gov/pub/special.requests/cpi/cpi.ai.txt)>. The annual average CPI is not available for 1998 and 1999. Therefore, an average of the CPI for January through November 1998 is used for 1998 and 1999.

Figure 2.4
OCR Budget as a Percentage of Total HHS Budget, 1980–1999



SOURCE: Information derived from U.S. Department of Health and Human Services, Office for Civil Rights, "OCR Budget and FTE Usage History, FY 80–FY 99 est.," Oct. 5, 1998, and Executive Office of the President, Office of Management and Budget, *Budget of the United States Government, Fiscal Year 2000: Historical Tables*, table 5.2, pp. 87–90.

appears to be for civil rights enforcement, which should be the first step in eliminating disparities in health care by race and ethnicity. HHS ignores the need for improved civil rights monitoring and enforcement, almost placing the onus for improved health care entirely on the minorities who face discrimination in access to health care.²⁸⁵

Civil rights efforts within HHS are also slighted in the proposed 15 percent increase in the Clinton administration budget for civil rights enforcement. Six agencies will share the majority of this increase: the Departments of Justice, Education, Labor, Housing and Urban Development, and Agriculture, and the U.S. Equal Employment Opportunity Commission.²⁸⁶ It is a serious omission to exclude HHS, and civil rights enforcement in the health care arena, from sharing in this increase, especially given its budget history.

As shown in figure 2.4, the OCR budget is only a small percentage of the entire HHS budget. In 1980 OCR accounted for 0.03 percent of the entire HEW budget. By 1999 OCR's percentage had fallen to 0.0054 percent of HHS' total budget. That civil rights enforcement is such a small part of the overall HHS budget highlights its low priority in the agency. Without proper enforcement of civil rights statutes and regulations, programs cannot operate effectively, as evidenced by the historical record of HHS.²⁸⁷ As a result, the health status of the nation as a whole is endangered.²⁸⁸

²⁸⁵ The director of OCR notes, however, that the Secretary and Deputy Secretary have supported OCR, by requesting increases in OCR's budget and fighting budget cuts aimed at OCR. Specifically, OCR informed the Commission that the Secretary intervened to increase OCR's budget request for FY 2000 to reflect a 7.3 percent over FY 1999. Perez letter, July 7, 1999, addendum, p. 1. Nonetheless, the Department has not addressed civil rights enforcement in relation to departmental initiatives on disparities in health, nor has it provided sufficient funding for OCR to participate fully in such initiatives.

²⁸⁶ Howard Kurtz, "Gore to Announce Plan to Hike Budget for Civil Rights by 15%" *Washington Post*, Jan. 18, 1999, p. A-7; "Administration to Seek \$663 Million for Civil Rights Enforcement, Gore Says," *Daily Labor Report*, Jan. 20, 1999, pp. AA-3, AA-4.

²⁸⁷ See chap. 1.

²⁸⁸ The director of OCR, appointed in February 1999, stated that Secretary Donna Shalala and Deputy Secretary Kevin Thurm have indicated to him their commitment for improving the resources of OCR. Perez interview, p. 5.

Although the FY 2000 budget purports to be concerned with improving access to health care and improving public health, there is no mention of civil rights.²⁸⁹ For example, efforts to reduce racial disparities in health status include \$135 million for health education, prevention, and treatment services for minorities, and an additional \$50 million to address HIV and AIDS in minority communities.²⁹⁰ In addition, the budget included a \$170 million increase for the Indian Health Service.²⁹¹ None of these initiatives recognizes that effective enforcement of civil rights laws by OCR can improve the health status and access to health care of Americans independent of departmental initiatives aimed at minorities. The FY 2000 budget also fails to take into account that, absent effective civil rights enforcement, racial disparities in health care will never be eliminated.

Staff Training

OCR does not have a comprehensive training plan for its staff; training needs are assessed on an as-needed basis.²⁹² In the 1996 report on Federal title VI enforcement, the Commission noted that OCR's staff training is extremely limited, consisting of on-the-job training for new staff and annual training seminars on new developments.²⁹³ Generally, the Complaint Resolution Manual, updated in December 1996, is used as a training manual for staff.²⁹⁴ Training is not formal. Using a team concept, equal opportunity specialists are trained by other staff who have more experience and who are more skilled than newer employees.²⁹⁵ For example, equal opportunity specialists (EOS) stated that branch chiefs provide on-the-job training in Region I.²⁹⁶

²⁸⁹ Executive Office of the President, Office of Management and Budget, *Budget of the United States Government, Fiscal Year 2000: Budget*, pp. 85-93.

²⁹⁰ *Ibid.*, p. 90.

²⁹¹ *Ibid.*

²⁹² O'Brien and Mackey interview, p. 6.

²⁹³ USCCR, *Federal Title VI Enforcement*, pp. 232-33.

²⁹⁴ OPO interview, p. 8 (statement of Shepperd); HHS, OCR, Region IV, Information Request Reply, January 1999, p. 3 (hereafter cited as OCR, Region IV, Information Request Reply).

²⁹⁵ OPO interview, p. 29 (statement of Mackey).

²⁹⁶ OCR Region I EOS interview, p. 6.

Many of the OCR employees the Commission interviewed stated that training was not sufficient. One regional manager stated that agency efforts with regards to training have been "horrible."²⁹⁷ He stated that for the past 8–10 years there have been no extra funds for staff training. He believes his staff needs issue-oriented training, as well as a review of the regulations.²⁹⁸ An attorney stated that formal training would be a "morale booster" for investigative staff because they feel that they have been forgotten in the HHS hierarchy.²⁹⁹

Throughout the regions training has been insufficient. For example, in Region VII, most of the investigators have not had formal investigator training.³⁰⁰ An attorney in Region IV stated that EOS staff do not have sufficient policy guidance on disparate impact standards, and some investigators lack an overall clear understanding of these standards. He said that some headquarters documents on policies are too theoretical to be useful on a "practical" level.³⁰¹ He recommended that efforts and resources be channeled to train, educate, and inform EOS about the programs they are expected to investigate and analyze from a civil rights perspective. He also stated that supervisors should ensure the EOS' understanding of programs before an investigation or compliance review is conducted.³⁰²

In many cases, regional attorneys provide training on investigative techniques and other issues, but not consistently.³⁰³ For example, the attorney in Region VIII stated that 4 years ago the regional manager requested that she take examples from intake forms and other work done in that office and develop training plans for the regional staff. Currently, the regional attorney brings other issues to the regional manager's

attention that can be addressed through training.³⁰⁴ Another regional attorney said that cases usually create the need for training, and training is based on examples.³⁰⁵ For instance, charges are filed that will raise questions; training addressing these questions will then be provided, and then reference will be made back to the actual cases to look at why the case was handled correctly or incorrectly. Thus, according to this attorney, training is usually a joint effort between the attorney and the senior investigators.³⁰⁶

However, the attorney in Region VII stated that regular training has not been done in her office for the past 10 years, but there was probably too much training. Currently, training is more specific and addresses more timely issues than training provided in the past. She stated that attorneys provide training to the investigative staff based on the issue and the attorney's review of the evidence in a particular case.³⁰⁷ Another attorney stated that she provides training as the need arises, perhaps three to five times per year.³⁰⁸ Comparatively, the equal opportunity specialists in Region X stated that, because of their many years of experience in the civil rights field, they do not need much training.³⁰⁹

Training Provided by Headquarters

OCR staff noted that in the 1980s, when the budget was more flexible, they were able to conduct a 5-year series of training sessions for all regional and headquarters staff.³¹⁰ These training sessions involved going to each regional office and providing an overview of the civil rights statutes enforced by OCR and the antidiscrimination provisions of block grants. During the mid- to late-1980s, OCR also focused on evidentiary methods and the investigative process. During this time, the training sessions did not focus on individual statutes.³¹¹

²⁹⁷ Halverson interview, p. 7.

²⁹⁸ Ibid.

²⁹⁹ Simonitsch interview, p. 8.

³⁰⁰ OCR Region VII EOS interview, p. 5.

³⁰¹ Freeman interview, p. 3.

³⁰² Ibid.

³⁰³ Geer interview, p. 2; OCR Region I EOS interview, p. 6; Freeman interview, p. 2; Bill Rhinehart, attorney, Region III, Office of General Counsel, HHS, telephone interview, Feb. 24, 1999, p. 2 (hereafter cited as Rhinehart interview). The regional manager for Region VII stated that any staff training done in his office has been done by the regional attorney. Halverson interview, p. 7.

³⁰⁴ Golightly-Howell interview, p. 2.

³⁰⁵ Miyasato interview, p. 2.

³⁰⁶ Ibid.

³⁰⁷ Simonitsch interview, p. 4.

³⁰⁸ Miyasato interview, p. 2.

³⁰⁹ OCR Region X EOS interview, p. 11.

³¹⁰ OPO interview, p. 3 (statement of Shepperd).

³¹¹ Ibid.

However, according to OCR staff, budget restrictions limited the amount of training provided during the 1990s.³¹² In 1993 and 1994 OCR conducted a major training initiative that consisted of several “civil rights forums” conducted for approximately 1 year on a quarterly basis. The forums were offered departmentwide and to funding recipients.³¹³ Approximately three forums were offered, each lasting a day. In these forums, OCR staff provided an overview of the civil rights authorities and regulations they enforce, provided fact sheets to attendees, and discussed cases they had handled.³¹⁴ OCR has not provided similar departmentwide civil rights training since then.³¹⁵

In May 1995, a 4-day training session was held at headquarters. Regional managers, regional attorneys, and investigators attended the training session, which focused on the investigative process and how title VI, section 504, and Hill-Burton apply to managed care.³¹⁶ Training sessions during the conference also focused on applying team building concepts to the case handling process.³¹⁷ Those who attended the training session were required to replicate the training in their respective offices.³¹⁸

In addition, the Departmental Appeals Board has provided training on alternative dispute resolution (ADR) to three OCR regional offices. The Appeals Board staff were planning a series of ADR training sessions for Office of General Counsel staff in the regions. OCR requested they extend the training to their staff in those offices. OCR reimbursed the Appeals Board staff for travel costs in return for the training.³¹⁹

In April 1998, OCR combined a conference with a training session. The session focused on the effects that hospital closures, reductions in services, and relocations have on minorities and

people with disabilities. The course was attended by regional managers, attorneys, and equal opportunity specialists.³²⁰ A training workbook was prepared for this training session by an outside contractor covering the analysis of civil rights data, including determining if data suggest discrimination has occurred, computing actual and estimated occupancy rates, testing for within-hospital segregation, and chi-square tests for statistical differences.³²¹

Headquarters OCR has seldom addressed training needs. In the late 1980s, OCR assessed the training needs in the regional offices. However, by the time the assessment was completed, no training funds remained.³²² In 1997 OCR again queried regional managers on their offices’ training needs. The responses revealed that regional offices desired training in several key areas, including computer technology (database, Internet, and word processing), interviewing skills, investigative skills, conflict resolution and negotiation, team building, presentation skills and conference planning, legal analysis, and writing.³²³

Training in the Regional Offices

According to the special assistant to the director of OCR, regional offices are responsible for ensuring that their staff have an informed understanding about OCR’s civil rights enforcement responsibilities.³²⁴ In addition, OCR regional offices frequently hold training sessions with staff of other HHS components in their regions, in which they provide an overview of the civil rights authorities OCR enforces and how those laws apply to the various HHS programs.³²⁵ However, staff in the regions noted that training is primarily informal.³²⁶ The pri-

³¹² Ibid.

³¹³ O’Brien and Mackey interview, p. 7 (statement of O’Brien).

³¹⁴ OPO interview, p. 11 (statement of Nelson).

³¹⁵ O’Brien and Mackey interview, p. 7 (statement of O’Brien).

³¹⁶ OPO interview, p. 3 (statement of Shepperd).

³¹⁷ Ibid., p. 4 (statement of Shepperd). See HHS, OCR, Agenda, “Regional/Headquarters Conference, May 15–19, 1995.”

³¹⁸ OPO interview, p. 4 (statement of Shepperd).

³¹⁹ Ibid., p. 8 (statement of Shepperd).

³²⁰ Ibid., p. 4 (statement of Shepperd).

³²¹ HHS, OCR, *Analysis of Civil Rights Data Training Workbook* (Silver Spring, MD: Support Services International, Inc., April 1998).

³²² OPO interview, pp. 5–6 (statement of Shepperd).

³²³ HHS, OCR, “1998 Regional Training Needs,” Mar. 12, 1998.

³²⁴ O’Brien and Mackey interview, p. 7 (statement of O’Brien).

³²⁵ OPO interview, p. 2 (statement of Shepperd).

³²⁶ Carter interview, p. 6; Caroline J. Chang, regional manager, Region I, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan.

mary obstacle to obtaining training is resources, according to regional staff.³²⁷

Regional staff attend conferences and seminars whenever possible,³²⁸ but training is not consistent across the regions. For example, Region I staff take advantage of courses offered at postsecondary education institutions in the area.³²⁹ Region IV provided its staff with a 3-day training program on alternative dispute resolution and a 2-day training program on computers.³³⁰ Many of the regions depend on briefings provided by other agencies (such as the Health Care Financing Administration and the Administration for Children and Families) and briefings provided by the regional attorneys.³³¹ In Region III, staff received training from the Department of Justice, the U.S. Equal Employment Opportunity Commission, and the Federal Mediation and Conciliation Service.³³² Region VIII provided several examples of training staff had received, which included training from OGC on the Americans with Disabilities Act, training on diversity jointly provided by HHS and the Internal Revenue Service, and training from a consultant on transracial adoption and foster care placements.³³³

Responses from the regional managers to the Commission's request for information indicate that staff have not been provided formal training

in many areas, such as compliance reviews.³³⁴ Regional staff stated that training is needed in several areas: current civil rights issues, title VI issues, quality of care, redlining, and disparities in treatments.³³⁵ In addition, one regional manager stated that his staff would benefit from training on the HHS civil rights regulations, current case law, and how to apply case law against the regulations.³³⁶

The lack of training resources has resulted in regional staff taking innovative approaches to acquiring training. For example, some regions partner with other Federal agencies and attend training sponsored by operating divisions and staff divisions.³³⁷ Region I obtained training in managed care and negotiation techniques "through contacts with training programs which were able to provide some free slots."³³⁸ Region X participated in many training sessions that were "free, in-house, or provided at minimal cost."³³⁹ The Region VII manager stated his office has worked with other civil rights agencies to receive training or they have "begged or borrowed to obtain funds" for training.³⁴⁰

An ad hoc approach to training ultimately will have a negative impact on the effectiveness of a civil rights enforcement agency. Staff must be trained in up-to-date investigations and negotiations techniques, must have refresher training on the laws they enforce, and must have training on the latest technology. Further, new staff must have formalized training in addition to on-the-job training if they are to be effective and to fully understand their responsibilities.

The state of staff training within OCR is abominable. Training is inconsistent and informal. Further, Federal agencies should not have to rely on "free slots" in vendor-provided training classes, nor should Federal agencies have to "beg and borrow" funds to obtain training. Training

12, 1999 (re: information request), p. 3 (hereafter cited as Chang letter).

³²⁷ Chang letter, p. 2; Paul F. Cushing, regional manager, Region III, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 11, 1999 (re: information request), p. 3 (hereafter cited as Cushing letter); OCR Region IV Information Request Reply, p. 3; Carmen Palomera Rockwell, regional manager, Region X, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Dec. 15, 1998 (re: information request), p. 3 (hereafter cited as Rockwell letter); Halverson interview, p. 7; OCR Region I EOS interview, p. 6.

³²⁸ Carter interview, p. 6. *See also* Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 14, 1999 (re: information request), enclosure, pp. 7-11 (hereafter cited as Kyle-Holmes letter).

³²⁹ Chang interview, p. 10.

³³⁰ Chretien interview, p. 12.

³³¹ Alfred J. Sanchez, acting regional manager, Region V, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 15, 1999 (re: information request), pp. 4-5 (hereafter cited as Sanchez letter).

³³² Cushing letter, pp. 2-3.

³³³ Kyle-Holmes letter, enclosure, pp. 7-11.

³³⁴ Chang letter, p. 2.

³³⁵ Carter interview, p. 6; Kyle-Holmes interview, p. 6.

³³⁶ Rouse interview, p. 1.

³³⁷ Carter interview, p. 6.

³³⁸ Chang letter, p. 3.

³³⁹ Rockwell letter, p. 3.

³⁴⁰ John W. Halverson, regional manager, Region VII, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 11, 1999 (re: information request), enclosure, p. 6 (hereafter cited as Halverson letter).

should be provided by experienced professionals, not regional attorneys and other staff who have other responsibilities.

Computer Technology

OCR uses the Internet to distribute information on its civil rights enforcement responsibilities. The OCR headquarters Web site provides regulations, press releases, information on filing a complaint, fact sheets, and other civil rights information.³⁴¹ It does not discuss title IX or provide for electronic filing of a complaint. In addition, 8 of the 10 regional offices provide civil rights information on their Web sites. Region X provides the most extensive information, including links to translated documents and links to other Federal civil rights information sources.³⁴² Region VII provides links to fact sheets, regulations, and information on how to file a complaint.³⁴³ Region VIII provides a brief description of all HHS components in the region, including OCR.³⁴⁴ All of the regions provide the name of the regional civil rights director. In addition, in 1994 Region II posted resources and other documents from one of its conferences on the *Diversity Rx* Web site.³⁴⁵ By using the Internet, OCR can make civil rights information available nationwide. However, the information OCR had on its Web site as of early 1999 was incomplete. A comprehensive electronic library of OCR's key documents remains an objective that OCR has yet to achieve.

Within the regional offices, regulations, policies, letters of finding, and other documents are available in electronic format.³⁴⁶ In addition, some regional offices have used databases to distribute information to the public. For example, to communicate significant civil rights policy

issues, in 1998 Region III developed a database and mailing list of all managed care contractors providing medicaid and CHIP services in the six States within the region.³⁴⁷

OCR is upgrading its computers and getting staff computer training.³⁴⁸ The Department decided that upgrading computer software and hardware and providing computer training to all staff is a high priority.³⁴⁹ OCR's regulations, fact sheets, and other information are available on the Internet at the HHS Web site.³⁵⁰ OCR staff also can access information on their Intranet, using an access code.³⁵¹ In 1999 OCR updated their computer hardware and software so that all staff are working with windows-based personal computers.³⁵²

OCR relies on its electronic Case Activity Tracking System (CATS) to manage its complaint investigation and compliance activity caseload.³⁵³ CATS was developed to improve the previous Case Information Management System (CIMS).³⁵⁴ The system is accessible by all the regions and allows OCR to track cases in various ways, such as by recipient, complainant, issue, and type of activity (e.g., complaint investigation, limited-scope review, full-scope review).³⁵⁵ The system also allows managers to manage case assignments. For example, CATS maintains information on the number of cases assigned to each equal opportunity specialist.³⁵⁶ The system also allows staff to prepare reports and submit annual operating plans electronically.³⁵⁷ However, the system tracks cases only by issue area (e.g., title VI, section 504, ADA, Hill-Burton, LEP), not by specific program.³⁵⁸

³⁴¹ See HHS, OCR, "Welcome to OCR," accessed at <<http://www.hhs.gov/progorg/ocr/ocrhmpg.htm>>.

³⁴² See HHS, OCR, Region X, "Welcome to OCR, Region X, Seattle, Washington," accessed at <<http://regx.os.dhhs.gov/ocr/ocrhome.htm>>.

³⁴³ See HHS, OCR, Region VII, "Welcome to OCR, Region VII, Kansas City, Missouri," accessed at <<http://www.hhs.gov/progorg/reg7/ocr/ocr7hp.htm>>.

³⁴⁴ See HHS, OCR, Region VIII, "A Brief Look at What We Do," accessed at <<http://www.hhs.gov:80/about/regions/reg8/whatwedo.html>>.

³⁴⁵ HHS, OCR, Region II, Jan. 21, 1999 (re: response to USCCR information request), index of attached documents.

³⁴⁶ Cushing interview, p. 9; Kyle-Holmes interview, p. 8.

³⁴⁷ Cushing letter, p. 3.

³⁴⁸ Garrison and Guerrero interview, p. 5 (statement of Garrison).

³⁴⁹ OPO interview, p. 7 (statement of Shepperd).

³⁵⁰ OPO interview, p. 24 (statement of Mackey). See HHS Web site at <<http://www.dhhs.gov>>.

³⁵¹ OPO interview, pp. 24–25 (statement of O'Brien).

³⁵² Perez letter, July 7, 1999, addendum, p. 7.

³⁵³ Data from the Case Activity Tracking System is presented in chap. 4.

³⁵⁴ OCR, *CATS Procedures Manual*, p. 1.

³⁵⁵ Chretien interview, p. 6; see also OCR, *CATS Procedures Manual*.

³⁵⁶ OCR Region II EOS interview, p. 5.

³⁵⁷ OCR, *CATS Procedures Manual*.

³⁵⁸ Chang interview, pp. 2, 11.

Despite OCR's efforts to manage and assess data and information with the help of computer technology, OCR regions, such as Region I and Region IX, do not maintain data on the names or the total number of HHS recipients within the region.³⁵⁹ According to the regional manager in Region I, the region's database does not retain any information on a consistent basis for HHS recipients, except for medicare providers who receive a pregrant/precertification review by OCR in conjunction with HCFA³⁶⁰ and reimbursement funds from HCFA. The regional manager said that her staff will not know about particular recipients (except for medicare providers) who reside in Region I and receive funds from NIH or HRSA, for instance, unless the region is conducting a complaints investigation or compliance review.³⁶¹

Although the regional offices are networked to OCR headquarters, use of computer technology appears to be inconsistent throughout the regions. Equal opportunity specialists in Region IX stated that their office makes full use of technology.³⁶² The manager for Region II stated that the region has "serious" technology problems.³⁶³ The manager for Region VII stated that some data are not available on the computer, and although complaints are entered into a computer, the office maintains a manual log of complaints received.³⁶⁴

Staff Recommendations

In interviews with regional OCR staff, the Commission asked what recommendations the staff would make for improving HHS civil rights enforcement. Their overall concern was with resources. Almost all regional staff stated that OCR needs more staff and financial resources.³⁶⁵

Several staff stated that there are many issues they cannot address, such as title IX, title VI, and managed care, because of limited resources.³⁶⁶ Other recommendations fell into the following categories:

- *Title VI Issues.* Many regional staff members stated that more attention should be focused on title VI issues.³⁶⁷ There is a need to focus more on certain groups, such as African Americans, and to address more languages than it currently does with regard to limited-English-proficiency issues.³⁶⁸ The Region VIII manager stated that the title VI regulations could be more explicit.³⁶⁹ Region X EOS said that the title VI regulations need to be clearer on LEP issues.³⁷⁰
- *Improved Communications.* Region II staff recommended that other regions create an interagency group of civil rights staff from government agencies in their region. Such a group would facilitate the sharing of information and improve communication within the region.³⁷¹ Other staff noted the need for better communication with the Federal Mediation and Conciliation Service.³⁷² Region VIII staff echoed the need to partner with other civil rights agencies. They also recommended increasing communication among the regional offices, and that a newsletter be developed.³⁷³ The Region I manager stated that more frequent communication with headquarters is needed, and Region I staff said that headquarters' responses should be more timely.³⁷⁴ Region I staff also suggested that branch chiefs from all regions have regular meetings to share ideas and inform

³⁵⁹ Rockwell letter, p. 11; Pollack interview, p. 10.

³⁶⁰ See, e.g., Chang interview, p. 11. See chap. 4, for a discussion of the precertification review of facilities and other health care providers that accept reimbursement from HCFA for treating medicare beneficiaries.

³⁶¹ Chang interview, p. 11.

³⁶² Annis Arthur, Bud Ho, and Marla Sagatelian, equal opportunity specialists, Region IX, OCR, HHS, telephone interview, Feb. 18, 1999, p. 6 (hereafter cited as OCR Region IX EOS interview).

³⁶³ Carter interview, p. 7.

³⁶⁴ Halverson interview, p. 8.

³⁶⁵ OCR Region II EOS interview, p. 7; Chretien interview, p. 13; OCR Region VIII EOS interview, p. 10; Golightly-

Howell interview, p. 10; Chang interview, p. 13; Pollack interview, p. 10; OCR Region IX EOS interview, p. 7; Freeman interview, p. 11; Halverson interview, p. 9.

³⁶⁶ Rouse interview, p. 2; OCR Region VI EOS interview, p. 4; Kyle-Holmes interview, p. 8; Cushing interview, p. 10.

³⁶⁷ OCR Region VI EOS interview, p. 4; Kyle-Holmes interview, p. 8.

³⁶⁸ Carter interview, p. 8.

³⁶⁹ Kyle-Holmes interview, p. 3.

³⁷⁰ OCR Region X EOS interview, p. 14.

³⁷¹ OCR Region II EOS interview, p. 7.

³⁷² OCR Region VII EOS interview, p. 10.

³⁷³ OCR Region VIII EOS interview, p. 10.

³⁷⁴ Chang interview, p. 13; OCR Region I EOS interview, p. 7.

one another of pertinent issues.³⁷⁵ In an interview with the Commission, the recently appointed director of OCR acknowledged that OCR staff have indicated the need for improved communications, and he has initiated several steps to address this issue, including holding monthly meetings with headquarters staff, weekly meetings with regional managers, and bimonthly case review sessions with regional staff.³⁷⁶

- *Compliance Reviews and Investigations.* For case investigations, one attorney stated that he thinks attorneys should be more involved in intake.³⁷⁷ In addition, less emphasis should be placed on closing cases, and more emphasis placed on taking time to close a case properly.³⁷⁸ One regional manager said that more emphasis should be placed on managed care issues.³⁷⁹ An attorney stated that there should be a list of recipients that have had complaints filed against them in the past and the status of such complaints, so that HHS can be aware of such issues when granting Federal funds.³⁸⁰ Another attorney said that all investigators should be attorneys.³⁸¹
- *Policy and Guidance.* Staff had several recommendations concerning policy and guidance.³⁸² Many of the attorneys and staff stated that the LEP guidance should be improved.³⁸³ The Region II and Region X attorneys stated that policy guidance in the area of disparate impact would be useful.³⁸⁴ Other suggestions included policy on the “most integrated setting” issue (related to the Ameri-

cans with Disabilities Act³⁸⁵ and the Multi-ethnic Placement Act³⁸⁶) and title VI.³⁸⁷ Region VIII staff recommended that summaries of policy guidance be developed that can be distributed to recipients.³⁸⁸ Region III staff suggested that there be a headquarters office that is responsive to program needs. For example, there should be subject matter specialists who are knowledgeable about current issues and who are thinking beyond the present.³⁸⁹ The Region III manager added that one of the limitations of OCR headquarters staff is that they have not had the field investigative experience to be able to offer guidance.³⁹⁰

- *Enforcement Tools.* One attorney stated that OCR needs a stronger enforcement tool than it currently has. This individual noted that the threat of cutting Federal funding is empty because it involves such a cumbersome process. At the least, HHS needs a more streamlined process of suspending Federal funds.³⁹¹ EOS said that they would like subpoena power and to be able to provide right to sue letters.³⁹²
- *Training.* Most employees said that there is a need for more training.³⁹³ Areas suggested included: title VI health care issues, case law, managed care issues, investigative techniques, and the difference between disparate impact and disparate treatment.³⁹⁴ One attorney stated that staff performance needs to be improved, although training is not needed.³⁹⁵ The regional manager for Region VI stated that training would be useful on the regulations, case law, and the applica-

³⁷⁵ OCR Region I EOS interview, p. 7.

³⁷⁶ Perez interview, pp. 2–3. See also Perez letter, June 3, 1999, enclosure, “Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions,” p. 8.

³⁷⁷ Geer interview, p. 5.

³⁷⁸ Ibid., p. 6.

³⁷⁹ Kyle-Holmes interview, p. 5.

³⁸⁰ Miyasato interview, p. 8.

³⁸¹ Stewart Graham, attorney, Region I, OCR, HHS, telephone interview, Feb. 22, 1999, p. 2.

³⁸² OCR Region VII EOS interview, p. 10; Simonitsch interview, p. 3; Golightly-Howell interview, p. 5; Miyasato interview, p. 3; Freeman interview, p. 11.

³⁸³ Morales interview, p. 6; OCR Region VIII EOS interview, p. 10.

³⁸⁴ Morales interview, p. 3; Miyasato interview, p. 4.

³⁸⁵ Pub. L. No. 101–336, 104 Stat. 327 (codified at 42 U.S.C. §§ 12101–12213 (1994)).

³⁸⁶ Codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997).

³⁸⁷ Morales interview, p. 3; Kyle-Holmes interview, p. 7.

³⁸⁸ OCR Region VIII EOS interview, p. 10.

³⁸⁹ OCR Region III EOS interview, p. 7.

³⁹⁰ Cushing interview, p. 10.

³⁹¹ Geer interview, p. 5.

³⁹² OCR Region VII EOS interview, p. 10.

³⁹³ Ibid., p. 5.

³⁹⁴ OCR Region VI EOS interview, p. 4; Kyle-Holmes interview, p. 6; Rhinehart interview, pp. 2, 4.

³⁹⁵ Simonitsch interview, p. 3.

tion of case law to the regulations.³⁹⁶ Other staff said that refresher training was needed to address new ideas and new ways of handling cases.³⁹⁷

- *Outreach, Education, and Technical Assistance.* Equal opportunity specialists stated that they need to increase outreach activities locally to raise awareness of civil rights issues in health care.³⁹⁸ They also stated that new informational materials are needed for distribution to recipients, complainants, beneficiaries, and the general public.³⁹⁹ EOS staff also suggested that there should be a reemphasis at the national level on methods of administration so that States' responsibili-

ties are regulated.⁴⁰⁰ The new director of OCR indicated that technical assistance is a crucial part of every OCR employee's job. One of his goals is to ensure that OCR's constituents are aware of OCR's role and know how to contact OCR for assistance.⁴⁰¹

The recommendations of the staff themselves show the deficiencies within the administrative operations of OCR. A deficiency in one area clearly leads to other deficiencies in other areas, resulting in an ineffective program. Budget and staffing problems both result in and are exacerbated by inadequate strategic planning and improper oversight of the regional offices.

³⁹⁶ Rouse interview, p. 1.

³⁹⁷ OCR Region I EOS interview, p. 7.

³⁹⁸ OCR Region VIII EOS interview, p. 10.

³⁹⁹ Ibid.

⁴⁰⁰ OCR Region VI EOS interview, p. 4.

⁴⁰¹ Perez interview, p. 4.

Chapter 3

Implementing Civil Rights Provisions: OCR's Rulemaking and Policy Development

*"OCR has provided a limited development of title VI policy for HHS-funded programs . . . When HHS was formed, it lacked individual civil rights policies, precedents, standards, and procedures necessary to operate an effective civil rights enforcement program. Efforts to establish such foundations have never been completed."*¹

The Federal Government has created the necessary legislation to provide equal access to the Nation's health care system. These measures have sought to ensure equal access to quality health care for every American, particularly focusing on the need to improve the health status of women, minorities, the elderly, and other economically compromised segments of our society. The laws comprise an intricate framework that incorporates both civil rights statutes and health care program legislation. The civil rights statutes include title VI of the Civil Rights Act of 1964,² title IX of the Education Amendments of 1972,³ and the nondiscrimination provisions⁴ of the HHS block grant statutes⁵ contained in the

Omnibus Reconciliation Act of 1981.⁶ Operating in conjunction with the civil rights legislation are laws designed to ensure quality health care service delivery, such as titles VI and XVI of the Public Health Service Act,⁷ the Emergency Treatment and Active Labor Act of 1985,⁸ and health care funding programs such as medicaid and medicare designed to assist specific groups of individuals.⁹

In the health care setting, the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) implements and enforces title VI, title IX, the community assurance provision of the Hill-Burton Act, and the nondiscrimination provisions in block grant programs to ensure that recipients of HHS funds, including private physicians, hospitals, nursing homes, managed care organizations, research programs, and health care financing programs, refrain from discriminating against minorities and women.¹⁰ OCR implements these laws largely

¹ U.S. Commission on Civil Rights (USCCR), *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, June 1996, pp. 224–25 (hereafter cited as USCCR, *Federal Title VI Enforcement*).

² Pub. L. No. 88–352, tit. VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d–2000d–7 (1994)).

³ Pub. L. No. 92–318, tit. IX, 86 Stat. 373 (codified as amended at 20 U.S.C. §§ 1681–1688 (1994)).

⁴ Pub. L. No. 97–35, sec. 901, §§ 1908, 1918, sec. 2192(a), §§ 708, 2606, 677, 95 Stat. 357, 542, 551, 825, 900, 516 (codified as amended at 42 U.S.C. §§ 300x–7(a)(1)–(2); 300w–7(a)(1)–(2); 708 (a)(1)–(2); 8625(a); 9906(a) (1994 & Supp. II 1996)). These laws contain provisions requiring nondiscrimination on the basis of race, color, national origin, sex, and religion.

⁵ Pub. L. No. 97–35, § 901, § 2192(a), §§ 2601–2611, §§ 671–683, § 2352(a), 95 Stat. 357, 535, 543, 552, 818, 893, 511, 867 (1981) (codified as amended at 42 U.S.C. §§ 300w–300w–10; 300x–300x–63; 701–710; 8621–8629; 9901–9926; 1397–1397f (1994 & Supp. II 1996)). The social services block grant, codified at 42 U.S.C. §§ 1397–1397f, does not contain a non-

discrimination provision. The primary care block grant, Pub. L. No. 97–35, sec. 901, §§ 1921–1932, 95 Stat. 357, 552 (codified at §§ 42 U.S.C. §§ 300y–300y10), was repealed in 1988. See chap. 4.

⁶ Pub. L. No. 97–35, 95 Stat. 357 (codified as amended in scattered sections of 5, 7, 8, 10, 12, 15, 19, 20, 22, 23, 24, 25, 26, 29, 31, 33, 35, 36, 38, 42, 45, 46, 47, 49, 50 U.S.C (1994 & Supp. II 1996)).

⁷ Pub. L. No. 79–725, 60 Stat. 1040 (1946) (codified as amended at 42 U.S.C. §§ 291–291–o (1994)) (enacting title VI of the Public Health Service Act), Pub. L. No. 93–641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q–300t (1994)) (enacting title XVI of the Public Health Service Act).

⁸ Section 1867 of the Social Security Act, Aug. 14, 1935, c. 531, as amended by Pub. L. No. 99–272, § 9121(b), 100 Stat. 164 (1986) (subsequently amended) (codified as amended at 42 U.S.C. § 1395dd (1994)).

⁹ Social Security Amendments of 1965, Pub. L. No. 89–97, titles XVIII & XIX, 79 Stat. 286, 343 (codified as amended at 42 U.S.C. §§ 1395–1396n (1994 & Supp. II 1996)).

¹⁰ The community assurance provision of the implementing regulations for titles VI and XVI of the Public Health Serv-

through rulemaking and policy development. The resultant regulations and policy guidance should provide the foundation for OCR's efforts to ensure nondiscrimination. Assessing the efforts OCR has undertaken in developing regulations and policies, and evaluating the extent to which OCR has provided clear, effective regulatory and policy guidance require a careful review of several key elements. These include the statutes OCR implements, OCR's development of standards and definitions that relate to discrimination in health care, and OCR's treatment in regulations and policies of key issues, such as managed care, physician staff privileges, limited English proficiency, and medical research.

Federal Laws Addressing Access to Health Care

Hill-Burton Act

For much of the post-World War II era, the Federal Government has maintained a consistent effort to make health care more accessible to more Americans. Soon after the end of the war, in 1946, Congress passed the Hospital Survey and Construction Act, popularly known as the Hill-Burton Act.¹¹ With this law, Congress sought to address a nationwide lack of adequate health care facilities, with a special focus on rural areas.¹² The original act established Federal grants for the construction of hospitals and other health care facilities. Congress stated that one of the main purposes of this legislation was:

to assist the several States in the carrying out of their programs for the construction and modernization of such public or other nonprofit community hospitals and other medical facilities as may be necessary, in

ice Act, known as the Hill-Burton Act, is codified at 42 C.F.R. § 124.603(a)(1) (1998).

OCR's mission also includes enforcement responsibilities for section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1994 & Supp. II 1996), the Age Discrimination Act of 1975, 42 U.S.C. §§ 6101-6107 (1994 & Supp. II 1996), and the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (1994 & Supp. II 1996). However, these statutes will not be addressed because they are outside the scope of this report.

¹¹ 42 U.S.C. §§ 291-291o (1994). A later act, the National Health Planning and Resources Development Act of 1974, codified at 42 U.S.C. §§ 300q-300t (1994), added a new title XVI to the Public Health Service Act. This effectively amended the Hill-Burton program to encompass titles VI and XVI of the Public Health Service Act.

¹² Hospital Survey and Construction Act, H.R. Rep. No. 2519 (July 13, 1946), reprinted in 1946 U.S.C.C.A.N. 1558, 1560.

conjunction with existing facilities, to furnish adequate hospital, clinic, or similar services to all their people.¹³

The Hill-Burton Act has been amended several times to address evolving health care concerns.¹⁴ In 1964 Congress amended Hill-Burton by passing the Hospital and Medical Facilities Amendments Act, which was incorporated into the Public Health Service Act as title VI.¹⁵ This amendment expanded the program's focus to include the modernization of existing facilities as well as the construction of new facilities.¹⁶ Six years later, Congress again amended the act to include loan and loan guarantee programs.¹⁷

In 1974 Congress amended Hill-Burton by passing the National Health Planning and Resources Development Act, which was incorporated into the Public Health Service Act as title XVI.¹⁸ At that time legislators believed that because of the success of Hill-Burton, additional hospital facilities were no longer needed.¹⁹ Congress intended title XVI as a replacement for title VI of the Public Health Service Act and attempted to contain health costs by curtailing unnecessary hospital expansions.²⁰ Title XVI required health facilities to obtain certificates of

¹³ 42 U.S.C. § 291(a) (1994).

¹⁴ See generally James F. Blumstein, "Court Action, Agency Reaction: The Hill-Burton Act as a Case Study," *Iowa Law Review*, vol. 69 (1984), p. 1227.

¹⁵ Hospital and Medical Facilities Amendments of 1964, Pub. L. 88-443; 78 Stat. 447 (codified as amended at 42 U.S.C. §§ 291-291o (1994)).

¹⁶ The proportion of funds expended for construction in 1947, which was 78 percent, compared with only 3 percent in 1974, demonstrates the shift in focus away from construction toward modernization between those years. S. REP. NO. 93-1285, reprinted in 1974 U.S.C.C.A.N. 7842, 7862.

¹⁷ The Medical Facilities Construction and Modernization Amendments of 1970, Pub. L. No. 91-296, supplemented the grants with loan and loan guarantee programs. These programs provided loan guarantees to non-Federal lenders on behalf of private health facilities, and direct loans to public agencies that are constructing or modernizing public hospitals. See National Health Planning and Resources Development Act of 1974, S. REP. NO. 93-1285, reprinted in 1974 U.S.C.C.A.N. 7842, 7863.

¹⁸ 42 U.S.C. §§ 300q-300t (1994).

¹⁹ S. REP. NO. 93-1285, reprinted in 1974 U.S.C.C.A.N. 7842, 7864. They did, however, recognize that many facilities still required modernization.

²⁰ 1982 *Congressional Quarterly Almanac*, p. 497. Facilities that had received funding under title VI were still governed under that title.

need from their States before funding would be approved.²¹

Congressional intent to use the Hill-Burton Act as a means of expanding health care access is reflected in the “uncompensated care assurance” and “community service assurance” provisions of the original act.²² These provisions required the States receiving funds to “provide for adequate hospital facilities for the people residing in a State, without discrimination on account of race, creed, or color, and shall provide for adequate hospital facilities for persons unable to pay therefor.”²³

Before passage of the 1964 Civil Rights Act, health care facilities openly discriminated against blacks, and these practices were supported by Federal money furnished through the Hill-Burton Act. Segregated facilities were eligible to receive Federal funding as long as they certified that there was a facility of “like quality” available for blacks.²⁴ Most hospitals excluded black patients and black physicians altogether, and the hospitals that did admit blacks put them in separate wards with black physicians and support staff. In 1963 the fourth circuit struck down this separate but equal funding policy as a violation of the equal protection clause of the 14th amendment.²⁵ The separate but equal language was subsequently excised from the community service assurance provision.²⁶

Implementation and Enforcement

Under the Hill-Burton implementing regulations promulgated by HHS, the community service assurance obligation also provided two other nondiscrimination mandates: (1) that a Hill-Burton facility must not withhold emergency medical services because of the inability to

pay of a patient residing in the service area;²⁷ and (2) that such a facility not discriminate against patient-beneficiaries of Federal, State, or local third-party payors (for example, medicaid or medicare patients).²⁸ The community service provision lasts in perpetuity.²⁹

Unlike the community service provision, the uncompensated care provision obligates the facility only for a 20 year period. For example, under the uncompensated care provision, if a hospital has received grant assistance with Hill-Burton funds, it must provide uncompensated services for 20 years from the time the construction of the facility was completed.³⁰ If such a facility has received loans through title VI, that facility must provide free service until the loan is repaid.³¹ In addition, the facility must be available to serve all persons living in its service area without discrimination with respect to the above categories.³² If an uninsured patient who resides in the facility’s service area requires emergency medical services, the facility must treat that patient.³³ Finally, the facility must afford equal access and quality treatment to medicaid and medicare patients, and to all other beneficiaries

²¹ *Ibid.*

²² See Pub. L. No. 79-725, § 2, sec. 622(f), 60 Stat. 1043 (1946). The regulations implementing these provisions, as amended, are codified at 42 C.F.R., pt. 124, subpts. F and G (1998).

²³ *Id.*

²⁴ *Id.*

²⁵ *Simkins v. Moses H. Cone Memorial Hosp.*, 323 F.2d 959, 969 (4th Cir. 1963) (en banc), *cert. denied*, 376 U.S. 938 (1964); see Sidney D. Watson, “Reinvigorating Title VI: Defending Health Care Discrimination—It Shouldn’t be so Easy,” *Fordham Law Review*, vol. 58 (1990), p. 940.

²⁶ See Pub. L. No. 88-443, § 3, sec. 603(e), 78 Stat. 447 (1964).

²⁷ 42 C.F.R. § 124.603(b) (1998). A patient who is employed in the service area is also protected, if the facility received funds under title XVI.

²⁸ 42 C.F.R. § 124.603(c)(2) (1998). See this chapter, “Hill-Burton Act, Rulemaking and Policy Development” section, for a discussion on Hill-Burton rulemaking and policy development.

²⁹ The HHS regulation implementing the statute’s community assurance provision requires that “in order to comply with its community service assurance, a facility shall make the services provided in the facility or portion thereof constructed, modernized, or converted with Federal assistance under title VI or XVI of the Act available to all persons residing (and, in the case of facilities assisted under title XVI of the Act, employed) in the facility’s service area without discrimination on the ground of race, color, national origin, creed or any other ground unrelated to an individual’s need for the service or the availability of the needed service in the facility.” 42 C.F.R. § 124.603(a)(1) (1998).

³⁰ 42 C.F.R. § 124.501(b)(1)(i) (1998).

³¹ 42 C.F.R. § 124.501(b)(1)(ii) (1998).

³² 42 C.F.R. § 124.603(a)(1) (1998). If the facility received funding under title XVI of the Public Health Service Act, even patients that do not live in the area, but that work within its boundaries, are covered. See also Jane Perkins, “Race Discrimination in America’s Health Care System,” *Clearinghouse Review*, special issue, 1993, pp. 380-81.

³³ 42 C.F.R. § 124.603(b) (1998). If the facility received title XVI funds, a patient employed in the service area must also be given emergency services.

of government-sponsored health insurance programs.³⁴

The Hospital Survey and Construction Act continued to provide Federal grants and loans for the construction of hospitals until 1974, when Congress discontinued appropriations for the program.³⁵ Hill-Burton has been responsible for increasing the number and modernity of health facilities across the Nation. However, enforcement of the act has not been effective in ensuring equal access to quality health care, according to some legislators, courts, and commentators.³⁶

For example, one commentator has stated that, since the 1970s, HHS' enforcement of the Hill-Burton obligations has failed, both qualitatively and quantitatively, to provide the level of care for indigent persons mandated by Congress.³⁷ This commentator cited several reasons for the ineffectiveness of the Hill-Burton uncompensated care requirements. First, HHS failed to promulgate regulations to define and enforce the uncompensated care and community service obligations until the 1970s.³⁸ Second, although the Federal regulations permitted the Secretary to designate a State agency to administer, monitor, and enforce Hill-Burton, the regulations did not require them to develop eligibility standards, issue hospital guidelines, or monitor compliance.³⁹ Third, because the statute and the regulations provided no punitive measures for viola-

tions, there was little incentive for hospitals to comply.⁴⁰

Despite HHS' apparent failure to clarify Hill-Burton requirements, courts have allowed private citizens to sue health care facilities that have violated the uncompensated care and community service assurance provisions.⁴¹ However, these plaintiffs have had mixed success.⁴²

Title VI of the Civil Rights Act of 1964

In 1964, some 18 years after passage of the original Hill-Burton Act, Congress passed the most comprehensive civil rights legislation it had enacted in nearly 100 years. Title VI of the Civil Rights Act of 1964 prohibits race, color, and national origin discrimination in any federally assisted program or activity.⁴³ Its objective is to prohibit discrimination by recipients of Federal funds against the intended beneficiaries of those funds. Federal funds assist State and local governments in almost every area of domestic public spending, including income support, infrastructure, public education, law enforcement, and social services.

The nondiscrimination mandate of title VI reaches the vast majority of actors in the health care industry because of the widespread distribution of medicaid, medicare part A, and other HHS program funds. For example, all health care providers that treat medicaid patients, including private physicians, hospitals, and nursing homes, are bound by title VI.⁴⁴ Similarly cov-

³⁴ 42 C.F.R. § 124.603(c)(2) (1998).

³⁵ See 1974 U.S.C.C.A.N. 7842-43.

³⁶ See Karen Treiger, note, "Preventing Patient Dumping: Sharpening the Cobra's Fangs," *New York University Law Review*, vol. 61 (1986) p. 1199 (citing *Newsom v. Vanderbilt Univ.*, 453 F. Supp. 401, 409 (M.D. Tenn. 1978), *aff'd in part, modified in part, and rev'd in part*, 653 F.2d 1100 (6th Cir. 1981)) ("The first enforcement regulations were finally promulgated in 1972, but then only after a series of lawsuits forced the agency into action."), *Cook v. Ochsner Found. Hosp.*, 61 F.R.D. 354, 361 (E.D. La. 1972) (by not issuing "any rulings, regulations, standards, or taking any specific action with respect to these hospitals," Secretary of HEW had failed to ensure that Hill-Burton facilities fulfilled their community service obligations); S. REP. NO. 93-1285, *reprinted in* 1974 U.S.C.C.A.N. 7842, 7900 (implementation of Hill-Burton by HEW and State agencies has been "sorry performance").

³⁷ *Ibid.*

³⁸ *Ibid.* (citing *Newsom v. Vanderbilt Univ.*, 453 F. Supp. 401, 409 (M.D. Tenn. 1978)).

³⁹ *Ibid.*

⁴⁰ *Ibid.*, pp. 1199-1200 (citing 42 U.S.C. 291c(e)(1) (1982 & Supp. II 1984)); 42 C.F.R. 124.606 (b) (1986)).

⁴¹ *Ibid.*, p. 1200, n. 102 (citing *Euresti v. Stenner*, 458 F.2d 1115, 1118 (10th Cir. 1972); *OMICA v. James Archer Smith Hosp.*, 325 F. Supp. 268 (S.D. Fla. 1971); *Cook v. Ochsner Found. Hosp.*, 319 F. Supp. 603 (E.D. La. 1970)). See generally Stephen E. Ronfeldt and Russell W. Gallaway, Jr., "Beneficiary-Based Enforcement of Federal Regulatory Programs: Strategies for Compelling Federal Agencies and Regulatees to Comply with Public Interest Laws," *Howard Law Journal*, vol. 2 (1983), p. 1365.

⁴² See, e.g., Treiger, "Preventing Patient Dumping," p. 1200, n.103 (citing *Perry v. Greater S.E. Community Hosp. Found.*, No. 725-71 (D.D.C. June 28, 1972)).

⁴³ The act provides that "[n]o person in the United States shall, on the ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 42 U.S.C. § 2000d (1994).

⁴⁴ See *id.* See also 42 U.S.C. § 2000d-4a (1994) (defining "program or activity" as "all of the operations of—(1)(A) a department, agency, special purpose district, or other in-

ered are all facilities that treat medicare patients.⁴⁵ Health care financing entities, such as managed care organizations, are also prevented from discriminating on the basis of race, color, or national origin if they contract to provide medicaid or medicare reimbursements.⁴⁶ Finally, research programs that receive HHS funding must not discriminate.⁴⁷ Title VI, therefore, is a crucial and potentially vital tool for ensuring non-discrimination and equal access to quality health care.

The legislative history of title VI makes clear that Congress passed the statute in part to ensure that Federal funds would no longer be used to support segregated health care facilities.⁴⁸ In speaking on behalf of enactment of title VI, Congressman Lindsay, reading from the House Judiciary Committee report accompanying the 1964 Civil Rights Act, referred specifically to discrimination on the basis of race in access to federally assisted health care delivery programs. Representative Lindsay described in vivid detail the racial discrimination pervasive in hospital construction and other medical care programs funded under the Hill-Burton Act:

strumentality of a State or local government, or the entity of such State or local government that distributes such assistance and each such department or agency (and each other State or local government entity) to which the assistance is extended, in the case of assistance to a State or local government; (2)(A) a college, university, other post-secondary institution, or a public system of higher education; or (B) a local educational agency (as defined in section 198(a)(10) of the Elementary and Secondary Education Act of 1965), system of vocational education, or other school system; (3) an entire corporation, partnership, or other private organization, or an entire sole proprietorship—(i) if assistance is extended to such corporation, partnership, private organization, or sole proprietorship as a whole; or (ii) which is principally engaged in the business of providing education, health care, housing, social services, or parks and recreation; or (B) the entire plant or other comparable, geographically separate facility to which Federal financial assistance is extended, in the case of any other corporation, partnership, private organization, or sole proprietorship; or (4) any other entity which is established by two or more of the entities described in paragraph (1), (2), or (3); any part of which is extended Federal financial assistance” (emphasis added)). Section 2000d-4a(3)(A)(ii) pertains to private organizations principally engaged in the business of providing health care, the category to which private physicians, private hospitals, and private nursing homes belong. 42 U.S.C. § 2000d-4a(3)(A)(ii) (1994).

⁴⁵ See 42 U.S.C. § 2000d-4a(3)(A)(ii) (1994).

⁴⁶ See *id.*

⁴⁷ See 42 U.S.C. § 2000d-4a(2)(A)-(3)(A) (1994).

⁴⁸ See 110 Cong. Rec. 1661 (1964) (statement of Rep. Lindsay).

Testimony before the House Judiciary Subcommittee . . . demonstrates that in many regions of the country, citizens are denied the equal benefits from Federal financial assistance programs because of their color. . . The Hill-Burton Act is a relevant case in point. Under this act, Federal funds are granted to assist in the construction and equipment of public and voluntary disease hospitals. Assistance is also provided for the establishment of other forms of medical care facilities such as nursing homes and public health centers. As of May 1963, \$2 billion have been devoted to this purpose by the Government. Despite the extent of this Federal contribution, however, example after example is available which establishes that Negroes are denied equal treatment under the act. Negro patients are denied access to hospitals or are segregated within such facilities. Negro doctors are denied staff privileges—thereby precluding them from properly caring for their patients. Qualified Negro nurses, medical technicians, and other health personnel are discriminated against in employment opportunities. The result is that the health standards of Negroes and, thereby, the Nation are impaired; and the incentive for Negroes to become doctors or to remain in many communities, after gaining a medical education, is reduced. . . In a related fashion, racial discrimination has been found to exist in vendor payment programs for medical care of public assistance recipients. Hospitals, nursing homes, and clinics in all parts of the [country] participate in these programs and, in some, Negro recipients have received less than equal advantage.⁴⁹

Continuing Relevance of the Title VI Mandate

More recently, the Attorney General has sought to reinvigorate the Federal Government's commitment to enforce title VI, especially with regard to policies and practices that create a discriminatory impact for a particular racial or national origin group. In a memorandum issued in July 1994 and circulated to all heads of departments and agencies that provide Federal financial assistance, the Attorney General stated:

This administration will vigorously enforce title VI. As part of this effort, and to make certain that title VI is not violated, each of you should ensure that the disparate impact provisions in your regulations are fully utilized so that all persons may enjoy equally the benefits of federally financed programs. . . Enforcement of the disparate impact provisions is an essential component of an effective civil rights compliance program. Individuals continue to be denied, on the basis of their race, color, or national origin, the

⁴⁹ *Ibid.*

full and equal opportunity to participate in or receive the benefits of programs assisted by Federal funds. Frequently discrimination results from policies and practices that are neutral on their face but have the effect of discriminating. . . . This Department is committed to productive and effective enforcement of the civil rights laws by each agency that extends Federal financial assistance. Facially neutral policies and practices that act as arbitrary and unnecessary barriers to equal opportunity must end. This was the goal of title VI when it became law and it remains one of the highest priorities of this Administration.⁵⁰

Recent studies indicating different health care access, outcomes, and quality of care along racial/ethnic lines illustrate the continuing relevance of the Attorney General's concerns and the need, as she directed Federal agencies, to use the title VI mandate to its fullest to ensure that neutral policies and practices do not result in a discriminatory impact based on race, color, or national origin.⁵¹

Implementation and Enforcement

Federal agency enforcement activities that use the title VI mandate are specifically prescribed under the law. As applied to programs operated by HHS, for example, title VI requires the agency to administer and enforce the statute's nondiscrimination provisions through the issuance of rules, regulations, or orders establishing the standards for compliance.⁵² HHS' rules, regulations, and orders must be "consistent with the achievement of the objectives" of the program or activity for which the financial assistance is being extended.⁵³ HHS' rules, regulations, and orders also must be approved by the President.⁵⁴ Executive Order 12250 provides the Attorney General with the authority vested in the President by title VI to approve all related agency rules, regulations,

and orders.⁵⁵ Effective implementation and enforcement of title VI should convince an HHS recipient that HHS will withhold Federal financial assistance if discrimination exists in its program, or if discrimination elsewhere in its operations affects the program,⁵⁶ unless the recipient agrees to remedy the discrimination.

Title VI allows HHS to enforce compliance with its rules, regulations, or orders either: (1) by terminating or refusing to grant or to continue financial assistance, or (2) by "any other means authorized by law."⁵⁷ No action of any kind, however, may be taken unless and until HHS has advised the recipient of its failure to comply and has determined that compliance cannot be achieved voluntarily.⁵⁸ If HHS selects termination or discontinuance of financial assistance as the means of enforcement, it may not terminate funds until and unless there has been an "express finding on the record, after opportunity for hearing," of noncompliance.⁵⁹ Further,

⁵⁰ U.S. Attorney General Janet Reno, U.S. Department of Justice, memorandum for Heads of Departments and Agencies that Provide Federal Financial Assistance, July 14, 1994 (hereafter cited as Reno, July 14, 1994 Memo).

⁵¹ See USCCR, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*, Vol. I. *The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999 (hereafter cited as USCCR, *The Health Care Challenge*, vol. I), chap. 2.

⁵² 42 U.S.C. § 2000d-1 (1994).

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ Exec. Order No. 12250, § 1-101, 3 C.F.R. 298 (1981), reprinted in 42 U.S.C. § 2000d-1 (1994). The authority and responsibility for coordinating title VI implementation and enforcement among all the agencies with title VI responsibility is vested in the Attorney General under Executive Order 12250. This order also applies to title IX of the Education Amendments of 1972, section 504 of the Rehabilitation Act of 1973, and "any other provision of Federal statutory law which provides . . . that no person in the United States shall, on the ground of race, color, national origin, handicap, religion, or sex, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance." Exec. Order No. 12250, § 1-101, 3 C.F.R. 298 (1981), reprinted in 42 U.S.C. § 2000d-1 (1994). For a further discussion of the Attorney General's title VI responsibility, see USCCR, *Federal Title VI Enforcement*, chap. 3. See also Brian K. Landsberg, "The Federal Government and the Promise of Brown," *Teachers College Record*, vol. 96, no. 4 (summer 1997), pp. 627-36.

⁵⁶ The Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, 102 Stat. 28 (title VI related provision codified at 42 U.S.C. § 2000d-4a (1994)), amended "the definition of program or activity" as it applies to the scope and coverage of title VI. See 42 U.S.C. § 2000d-4a (1994). In addition, the act's legislative history confirms the reach of the fund termination remedy. See U.S. Congress, Senate, Committee on Labor and Human Resources, Civil Rights Restoration Act of 1987, 100th Cong., 2d sess., S. Rep. No. 64, p. 20, reprinted in 1988 U.S.C.C.A.N. 3, 22. See USCCR, *Federal Title VI Enforcement*, chap. 2.

⁵⁷ 42 U.S.C. § 2000d-1 (1994).

⁵⁸ *Id.* See also *United States v. Baylor Univ. Med. Ctr.*, 736 F.2d 1039, 1050 (5th Cir. 1984), cert. denied, 469 U.S. 1189 (1985).

⁵⁹ 45 C.F.R. § 80.8(c) (1998).

its action must be limited in its effect to the particular recipient, or part thereof, and the particular program in which a violation has been found.⁶⁰ Once HHS has afforded notice to the recipient, an opportunity for a hearing, and thereafter ordered termination, discontinuance, or refusal to grant funds, it must file a written report justifying its action with the congressional committee having jurisdiction over the particular assistance program.⁶¹ HHS' action does not become effective until 30 days after the filing of the report.⁶²

Judicial Interpretation

As intended by Congress, courts have upheld termination of funding as an appropriate agency enforcement mechanism to be used when recipients are not in compliance with those rules and regulations.⁶³ However, courts have varied in their interpretations of what other measures are available to an agency. For example, some courts have held that an agency is entitled, under title VI, to enforce contractual assurances of compliance by a recipient.⁶⁴

Although title VI expressly provides for administrative enforcement only, lower courts have consistently recognized private suits, also known as private rights or causes of action, as a means of enforcing title VI.⁶⁵ Courts have allowed private individuals to initiate lawsuits under title VI because, although fund termination may serve as an effective deterrent to recipients, it

may leave the victim of discrimination without a remedy.⁶⁶

Plaintiffs in private causes of action enforcing title VI cannot terminate Federal funding,⁶⁷ but they may be able to receive equitable or monetary relief, depending on the facts of their cases.⁶⁸ Equitable relief means that a plaintiff may use the court's power to force the defendant to take a specific action or to refrain from taking a specific action.⁶⁹ Courts may award equitable relief when a plaintiff proves a case of discrimination.⁷⁰ An example of equitable relief in the title VI health care context is the granting of an injunction to stop a hospital from renovating a facility that is inaccessible to minorities. Monetary, or compensatory relief, takes the form of money paid to a plaintiff as compensation for harm done.⁷¹

For private claimants who allege discrimination resulting from policies or actions of a health care facility, one of the most promising aspects of title VI is that it may be used to establish a disparate impact claim.⁷² Disparate impact occurs when a facially neutral policy operates in a way that affects a protected class of citizens disproportionately. Under title VI, a health care plaintiff who is claiming disparate impact need not

⁶⁰ *Id.*

⁶¹ *Id.*

⁶² *Id.*

⁶³ *See, e.g.,* Board of Public Instruction v. Finch, 414 F.2d 1068, 1076-78 (5th Cir. 1969).

⁶⁴ *See, e.g.,* United States v. Marion County Sch. Dist., 625 F.2d 607, 617 (5th Cir. 1980), *reh'g denied*, 629 F.2d 1350 (5th Cir. 1980), *cert. denied*, 451 U.S. 910 (1981) (holding that the United States is entitled to sue to enforce contractual assurances of compliance with this section's prohibition, and is entitled to whatever relief is necessary to enforce such assurances).

⁶⁵ *See, e.g.,* Chester Residents Concerned for Quality Living v. Seif, 132 F.3d 925 (3rd Cir. 1997) (holding that a private right of action for disparate impact cases exists under the title VI regulations); Neighborhood Action Coalition v. City of Canton, 882 F.2d 1012, 1015 (6th Cir. 1989); Larry P. v. Riles, 793 F.2d 969, 977 n.3 (9th Cir. 1984); Montgomery Improvement Ass'n v. United States Dep't of Hous. and Urban Dev., 645 F.2d 291, 295-97 (5th Cir. 1981); Bossier Parish Sch. Bd. v. Lemon, 370 F.2d 847, 852 (5th Cir. 1967), *cert. denied*, 388 U.S. 911 (1967).

⁶⁶ *See, e.g.,* Cannon v. Univ. of Chicago, 441 U.S. 677, 705-06 (1979) (discussing the need to allow a private right of action under title IX of the Education Amendments of 1972).

⁶⁷ Watson, "Reinvigorating Title VI," p. 946.

⁶⁸ *See* Franklin v. Gwinnett County Public Schools, 503 U.S. 60, 70 (1992) (interpreting as support for monetary damages under title IX, the implicit view of a majority of the Court in Guardians Ass'n v. Civil Serv. Comm'n, 463 U.S. 582 (1986), that damages are available in title VI cases).

⁶⁹ *See, e.g.,* Latimore v. Contra Costa County, No. C 94-1257, slip op. at 32-33 (N.D. Cal. Aug. 1, 1994) (granting (but later dissolving due to changed circumstances) a preliminary injunction postponing construction of a hospital), *preliminary injunction dissolved*, Latimore v. Contra Costa County, No. C 94-1257 (N.D. Cal. Mar. 27, 1995), *dissolution aff'd*, 77 F.3d 489 (9th Cir. Feb. 1, 1996) (table case format), 1996 U.S. App. LEXIS 3524 (No. 95-15886).

⁷⁰ *See* Guardians Ass'n v. Civil Serv. Comm'n 463 U.S. 582, 612 (1983) (O'Connor, J., concurring); *id.* at 624-34 (Marshall, J. dissenting); *id.* at 635-39 (Stevens, Brennan, Blackmun, J.J., dissenting); Watson, "Reinvigorating Title VI," p. 953, and nn. 99-100.

⁷¹ The Supreme Court has held that this type of relief is only available where the plaintiff proves that the defendant purposefully discriminated. *Id.* at 584.

⁷² The Supreme Court has held that the title VI implementing regulations of HHS allow for discrimination claims based upon disparate impact. *Id.* at 589-93.

establish that a policy has a discriminatory motive in order to obtain relief. The plaintiff need only demonstrate that he or she is a member of a particular minority group that has been or could be affected at disproportionately high rates by the policy.

Although the disparate impact theory has opened the door for a wider array of discrimination causes of action, claimants still have their work cut out for them. Prevailing on a claim of disparate impact can be difficult because of the evidentiary burdens on the plaintiff. Once the plaintiff establishes that an adverse impact exists, the defendant must legally justify its actions by establishing a relationship between the discriminatory policy or practice and the defendant's stated objective.⁷³ However, if the defendant is able to justify the policy or practice, the burden shifts back to the plaintiff to demonstrate that there is a less discriminatory option available that is comparably effective.⁷⁴

The problems relating to the renovations, relocations, and closures of health care facilities exemplify some of the difficulties in relying on disparate impact as a cause of action under title VI. Three early claims in which plaintiffs attempted to use title VI impact discrimination to enjoin the closure of local hospitals were rejected by the courts.⁷⁵ More recently, one small victory suggests the continuing viability of title VI as an avenue for fighting recipient health care facilities.⁷⁶

⁷³ See, e.g., *Elston v. Talladega County Board of Education*, 997 F.2d 1394, 1413 (11th Cir. 1993) (requiring that the defendant demonstrate that its actions were necessary to meet a "legitimate, important goal integral to the defendant's institutional mission"). See also Daniel K. Hampton, note, "Title VI Challenges by Private Parties to the Location of Health Care Facilities: Toward a Just and Effective Action," *Boston College Law Review*, vol. 37 (May 1996), pp. 530-31 (discussing *Elston*, 997 F.2d, at 1394).

⁷⁴ See *ibid.*, p. 553, citing *Elston*, 997 F.2d at 1407; Watson, "Reinvigorating Title VI," pp. 965-66 (discussing the application of the burden of proof in the title VII employment discrimination context to title VI education cases).

⁷⁵ *Bryan v. Koch*, 627 F.2d 612, 616 (2d Cir. 1980); *NAACP v. Med. Ctr., Inc.*, 657 F.2d 1322, 1337 (3d Cir. 1981); *Gingras v. Lloyd*, 585 F. Supp. 684 (D. Conn. 1983).

⁷⁶ See *Latimore v. Contra Costa County*, No. C 94-1257, slip op. at 20 (N.D. Cal. Aug. 1, 1994) (stating that the defendant's burden is to show that the disparate impact was required by necessity . . . or that the challenged conduct has a manifest relationship to . . . health care objectives and granting (but later dissolving due to changed circumstances) a preliminary injunction postponing construction of a hospi-

Medicare and Medicaid Programs

In 1965 Congress created the Medicare and Medicaid programs as titles XVIII and XIX, respectively, of the Social Security Act.⁷⁷ The purpose of these programs was to provide a coordinated approach for health insurance and medical care for the aged, and to expand medical services for the needy and the disabled.⁷⁸ The Medicaid program is a Federal program that awards grants to States to furnish medical assistance to indigent individuals who are aged, blind or otherwise disabled, or who are members of families with dependent children.⁷⁹ In return for this Federal assistance, States are required to develop a State plan of operation and oversight that is approved by the Secretary of Health and Human Services.⁸⁰ Under this plan, the State is responsible for reviewing the appropriateness and quality of care provided to Medicaid pa-

tal in a predominately white, middle class part of the county), *preliminary injunction dissolved*, *Latimore v. Contra Costa County*, No. C 94-1257 (N.D. Cal. Mar. 27, 1995), *dissolution aff'd*, 77 F.3d 489 (9th Cir. Feb. 1, 1996) (table case format), 1996 U.S. App. LEXIS 3524 (No. 95-15886). *But see* *Mussington v. St. Luke's-Roosevelt Hospital Center*, 824 F. Supp. 427, 432-433 (S.D.N.Y. 1993), *aff'd*, 18 F.3d 1033 (2d Cir. 1994) (per curiam) (rejecting a title VI relocation claim on the ground that it was time-barred because the claim had been filed over 3 years from the time the consolidation plan had "gained a significant degree of certainty").

⁷⁷ Social Security Amendments of 1965, Pub. L. No. 89-97, titles XVIII & XIX, 79 Stat. 286, 343 (codified as amended at 42 U.S.C. §§ 1395-1396n (1994 & Supp. II 1996)).

⁷⁸ Social Security Amendments of 1965, S. REP. NO. 404 (1965), *reprinted in* 1965 U.S.C.C.A.N. 1943. The Medicare program consists of Parts A and B. Part A, called the Medicare hospital insurance (HI) program, pays for hospital, nursing home, home health, and hospice services. Part B, the Medicare supplemental medical insurance (SMI) program, covers physicians' services and a variety of other items and services including outpatient hospital services, home health care, physical and occupational therapy, prosthetic devices, durable medical equipment, and ambulance services. Barry R. Furrow, Thomas L. Greaney, Sandra H. Johnson, Timothy S. Jost, and Robert L. Schwartz, eds., *Health Law: Cases, Materials, and Problems* (St. Paul, MN: West Group, 1997), p. 842. See also Pub. L. No. 89-97, §§ 1811-1817, 1831-1844, 79 Stat. 286 (codified as amended at 42 U.S.C. §§ 1395-1395a, 1396-1396a (1994 & Supp. II 1996)).

⁷⁹ 42 U.S.C. §§ 1396-1396a (1994). See *Linton v. Comm'r of Health and Env't*, 779 F. Supp. 925, 928 (M.D. Tenn. 1990) (describing the purposes of the Medicaid statute), *remanded*, 973 F.2d 1311 (6th Cir. Tenn. 1992), *subsequent appeal, aff'd, sub. nom.*, *Linton by Arnold v. Comm'r of Health and Env't*, 65 F.3d 508 (6th Cir. Tenn. 1995).

⁸⁰ 779 F. Supp. at 928.

tients, and for determining whether the recipient health care providers meet the requirements for participation in the program.⁸¹

The Social Security Amendments Act does not contain any general nondiscrimination provisions, but the regulations implementing it require medicare and medicaid providers to abide by the nondiscrimination edicts of title VI of the Civil Rights Act of 1964, section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, and their associated regulations.⁸² If a provider is found to have discriminated in violation of any of these statutes, its provider contract is considered invalid, and it risks losing Federal funds.⁸³

Because medicare and medicaid are Federal assistance programs, victims of impact discrimination based upon race, color, or national origin may receive equitable relief under title VI. A successful example of this right of action is *Linton v. Commissioner of Health and Environment*,⁸⁴ a class action suit in which one of the plaintiffs, an elderly black woman, enjoined a Tennessee policy that limited the number of beds in medicaid-participating nursing homes. The U.S. District Court for the Middle District of Tennessee found that because of the higher incidence of poverty in the black population, and the concomitant increased dependence on medicaid, the bed-limitation policy impacted blacks disproportionately.⁸⁵

Title IX of the Education Amendments of 1972

In the early 1970s, Congress continued to enact civil rights legislation requiring nondiscrimi-

nation in a variety of contexts.⁸⁶ In 1972 Congress passed title IX of the Education Amendments Act.⁸⁷ The language of title IX was patterned after that of title VI, but the scope of title IX was limited to sex discrimination in educational programs.⁸⁸

Title IX's legislative history indicates that Congress enacted the statute in part as a response to congressional testimony reporting widespread discrimination against women in higher education, including medical school programs.⁸⁹ Chaired by Representative Edith Green of Oregon, hearings were held in conjunction with Congress' consideration of section 805 of H.R. 16,098, a bill that would have added the word "sex" to title VI of the Civil Rights Act of 1964.⁹⁰ Sponsors of the new legislation sought to accommodate members of Congress opposed to a comprehensive prohibition against sex discrimination in all federally assisted programs.⁹¹

In his introduction of title IX on the Senate floor, Senator Birch Bayh, the bill's sponsor, emphasized the seriousness of gender discrimination in medical school admissions.⁹² Senator Bayh stated that from 1966 to 1967, only 18 out of 89 medical schools in the country had more than 10 percent female students.⁹³ Moreover, the Senator introduced statistics demonstrating that although the percentage of female applicants to medical schools increased more than 300 percent

⁸¹ *Id.* at 929 (citing 42 U.S.C. § 1396a(a)(33) and 42 C.F.R. § 442).

⁸² 42 C.F.R. § 489.10 (1998). The associated regulations are found in 45 C.F.R. pt. 80 (1998) (title VI); 45 C.F.R. pt. 84 (1998) (section 504); and 45 C.F.R. pt. 90 (1998) (Age Discrimination Act). In addition, as regards the Vaccines for Children Program, the medicaid statute requires States to identify, with respect to any population of vaccine-eligible children, a substantial portion of whose parents have a limited ability to speak the English language, those program-registered providers who are able to communicate with the population involved in the language and cultural context that is most appropriate. See 42 U.S.C. § 1396(s)(c)(3)(B) (1994).

⁸³ See *Linton*, 779 F. Supp. at 935 (citing 42 C.F.R. pts. 80, 84, and 90).

⁸⁴ See *id.* at 932.

⁸⁵ *Id.*

⁸⁶ See, e.g., section 504 of the Rehabilitation Act of 1973, Pub. L. No. 93-112, title V, § 504, 87 Stat. 394 (codified as amended at 29 U.S.C. § 794 (1994)) (providing for nondiscrimination on the basis of disability in federally assisted programs); title IX of the Education Amendments of 1972, 20 U.S.C. §§ 1681-1688 (1994) (requiring nondiscrimination on the basis of sex in federally assisted education programs); Equal Educational Opportunity Act of 1974, Pub. L. No. 93-380, 88 Stat. 515 (codified as amended at 20 U.S.C. §§ 1701-1721 (1994)) (prohibiting States from denying equal educational opportunity to an individual on account of race, color, sex, or national origin).

⁸⁷ 20 U.S.C. §§ 1681-1688 (1994).

⁸⁸ 20 U.S.C. § 1681(a) (1994).

⁸⁹ See *Discrimination Against Women: Hearings on § 805 of H.R. 16,098 Before the Special Subcommittee on Education of the House Committee on Education and Labor, 91st Cong., 2d Sess.* (1970).

⁹⁰ 42 U.S.C. §§ 2000d-2000d-7 (1994).

⁹¹ See 117 Cong. Rec. 30, 407, 30, 408 (1971); 118 Cong. Rec. 5803, 5807, 18, 437 (1972) (remarks of Sen. Bayh); 117 Cong. Rec. 39, 256 (1971) (remarks of Rep. Green).

⁹² 118 Cong. Rec. 5803 (statement of Sen. Bayh).

⁹³ *Ibid.*

between 1929 and 1965, the percentage of those that were accepted actually declined from 65.5 percent in 1929 to 47.7 percent in 1965.⁹⁴

Implementation and Enforcement

Title IX and its implementing regulations have been the most influential pieces of Federal legislation and policy to effect positive change in higher education for women, offering a means for women to gain access to such fields as law, medicine, and business. The HHS regulations implementing title IX outline criteria for what constitutes compliance with title IX, and, thus, nondiscrimination under that law.⁹⁵ The regulations address many educational practices, particularly admission to educational programs, including university hospital teaching and research programs. They also deal with topics such as comparable facilities and services.⁹⁶

In addition, the Civil Rights Restoration Act of 1987,⁹⁷ which applies to title IX and title VI, means that the title IX nondiscrimination mandate applies on an institutional basis, rather than a program-specific one.⁹⁸ Thus, with certain exceptions,⁹⁹ title IX's nondiscrimination mandate reaches any institution that receives Federal funds for an educational program. Although the primary agency making such grants is the Department of Education, the statute is enforced by any Federal agency that grants such funds, including the Department of Health and Human Services.¹⁰⁰

The enforcement procedures under title IX are essentially the same as those under title VI.¹⁰¹ The primary method of enforcement is fund termination, although enforcement may

occur by any method authorized by law.¹⁰² Funds cannot be terminated until attempts to foster compliance have failed, and the recipient has been afforded the opportunity for a hearing.¹⁰³

The language of the title IX statute is similar to that of title VI, reflecting Congress' view that laws proscribing gender, race, color, and national origin discrimination are based upon the underlying precept of equal rights under the law. The courts have also demonstrated the link between title IX and title VI by interpreting them analogously.¹⁰⁴ The two statutes are similar in both substantive protections and enforcement procedures. For example, title IX, as well as title VI, reaches discrimination in employment.¹⁰⁵

Private rights of action are available,¹⁰⁶ in which plaintiffs may be awarded equitable and/or compensatory relief.¹⁰⁷ An example of equitable relief would be a case in which a university is ordered to admit a student whose application it had previously rejected discriminatorily. An example of compensatory relief might involve paying damages to a victim of sexual harass-

⁹⁴ Ibid. (Sen. Bayh, citing statistics from *Journal of Medical Education*, vol. 42, no. 1 (January 1967) and the Association of Medical Colleges *Datagram*, vol. 7, no. 8 (1966)).

⁹⁵ 45 C.F.R. pt. 86 (1998).

⁹⁶ *Id.*

⁹⁷ See Pub. L. No. 100-259, 102 Stat. 28 (codified at 20 U.S.C. §§ 1681, 1687, 1688; 29 U.S.C. §§ 706, 794; 42 U.S.C. §§ 2000d-4a (1994)) (amending title VI of the Civil Rights of 1964, title IX of the Education Amendments of 1972, and section 504 of the Rehabilitation Act of 1973).

⁹⁸ See 20 U.S.C. § 1687 (1994).

⁹⁹ See 20 U.S.C. § 1681(a)(1)-(9) (1994).

¹⁰⁰ See 45 C.F.R. pt. 80 (1998) (the existence of which evidences HHS' shared jurisdiction of title IX cases).

¹⁰¹ See 45 C.F.R. § 86.71 (incorporating the enforcement procedures of 45 C.F.R. §§ 80-6 to 80-11 and pt. 81).

¹⁰² 20 U.S.C. § 1682(1)-(2) (1994); 45 C.F.R. § 86.71 (1998) (incorporating the enforcement procedures of 45 C.F.R. §§ 80-6 to 80-11 & pt. 81).

¹⁰³ 20 U.S.C. § 1682 (1994); 45 C.F.R. § 86.71 (1998) (incorporating the enforcement procedures of 45 C.F.R. §§ 80-6 to 80-11 and pt. 81); 45 C.F.R. §§ 80.8-80.10.

¹⁰⁴ See *Gannon v. Univ. of Chicago*, 441 U.S. 677, 696-703 (1979) (stating that the congressional drafters of title IX explicitly assumed that it would be enforced in the same manner as title VI).

¹⁰⁵ See 42 U.S.C. § 2000d-3 (1994); 45 C.F.R. pt. 86, subpt. E (1998) (prohibiting employment discrimination under title IX); 45 C.F.R. § 80.3(c)(1)-(3) (prohibiting employment discrimination under title VI). The scopes of the nondiscrimination provisions differ, however. Title VI only applies to cases in which actual participants in Federal employment programs allege discrimination or where discrimination in employment causes discrimination to the beneficiaries. 45 C.F.R. § 80.3(c)(1)-(3). Title IX proscribes employment discrimination in any educational program. 45 C.F.R. § 86.51(a)(1)-(4).

¹⁰⁶ 441 U.S. at 688-89 (1979) (conferring a private right of action for gender discrimination under title IX).

¹⁰⁷ *Franklin v. Gwinnett County Public Schools*, 503 U.S. 60, 66-73 (1992) (citing *Bell v. Hood*, 327 U.S. 678, 684 (1946)) (holding that there is a presumption that when a federal statute provides a general right to sue against an invasion of legal rights, Federal courts may use any available remedy, and finding that Congress did not intend to limit the application of this presumption in title IX cases).

ment by a professor.¹⁰⁸ One important area in which title IX case law remains unsettled is disparate impact discrimination. Unlike the title VI enforcement regime, it is still uncertain whether plaintiffs must prove intentional discrimination to make a case under title IX.¹⁰⁹

Gender discrimination in educational programs relating to health could, in the long run, affect the quality of care given by health facilities. For example, if female applicants are denied admission to medical school because of discrimination, the effect would be to decrease the number of female doctors serving the public. This could eventually affect the way patients are treated. A limited number of plaintiffs who were denied admission to medical schools have brought suits under title IX.¹¹⁰

Another area in which gender discrimination impinges upon the quality of health care is clinical research. According to a number of commentators, many clinical trials of potential new drugs fail to use women as test subjects.¹¹¹ These

commentators assert that medical research project managers are hesitant to use females in testing drugs for three reasons. First, they believe that the difference between the male and female bodies is insignificant for their purposes.¹¹² Second, they fear being held liable if a woman or her unborn fetus is injured.¹¹³ Third, women are considered "unnecessarily complicated," making research trials that include them more time consuming, and more expensive.¹¹⁴ At least one commentator has suggested that failure to use female test subjects in federally assisted research is a violation of title IX.¹¹⁵

Nondiscrimination Provisions in Block Grant Statutes

Nine years after the passage of title IX, Congress again enacted legislation having significant implications for health care access of minorities and women. In 1981 Congress created block grants as part of the Omnibus Budget Reconciliation Act.¹¹⁶ The legislation consolidated the existing Federal grant programs of several agencies, including the Departments of Housing and Urban Development, Education, and Health and Human Services.¹¹⁷ Under the block grant regime, States had more freedom to tailor programs to meet their specific needs.¹¹⁸

HHS categorical programs were consolidated into seven block grants: the community services, the preventive health and health services, the

¹⁰⁸ See *id.* at 76 (holding that a high school student that had been sexually harassed by her teacher could receive compensatory damages).

¹⁰⁹ James S. Wrona, "Eradicating Sex Discrimination in Education: Extending Disparate-Impact Analysis to title IX Litigation," *Pepperdine Law Review*, vol. 21 (1994), p. 7 n. 30 (citing *Pfeiffer v. Marion Ctr. Area School Dist.*, 917 F.2d 779, 788 (3rd Cir. 1990)) (suggesting that if confronted with the issue, the third circuit would allow a disparate impact claim); *Sharif v. New York State Educ. Dep't*, 709 F. Supp. 345, 364 (S.D.N.Y. 1989) (awarding a preliminary injunction ordering the New York State Education Department from relying solely on SAT scores in awarding scholarships); *Haffer v. Temple Univ.*, 678 F. Supp. 517, 539-40 (E.D. Pa. 1987) (holding that discriminatory intent is not required for a title IX claim).

¹¹⁰ See, e.g., *Gannon v. University of Chicago*, 441 U.S. 677 (allowing a private right of action under title IX, although plaintiff lost on remand); *Lieberman v. Univ. of Chicago*, No. 79 C 3533 (N.D. Ill. Sept. 21, 1980), U.S. Dist. LEXIS 14078 at *5-7, *aff'd*, 660 F.2d 1185 (7th Cir. 1981), *cert. denied*, 456 U.S. 937 (1982) (holding that plaintiff's request for injunctive relief was moot and that compensatory damages are unavailable under title IX, thus not reaching the merits of plaintiff's case).

¹¹¹ See, e.g., Anna C. Mastroianni, "HIV, Women, and Access to Clinical Trials—Tort Liability and Lessons from EDS," *Duke Journal of Gender Law and Policy*, vol. 5, no. 1 (spring 1998), pp. 167-77; Karen Rothenberg, "Gender Matters: Implications for Clinical Research and Women's Health Care," *Houston Law Review*, vol. 32 (winter 1996), pp. 1201-72; Mary Bobinski, "Women and HIV: A Gender-Based Analysis of a Disease and Its Legal Regulation," *Texas Journal of Women and Law*, vol. 3 (1994), p. 22, n. 55; R. Alta Charo, "Protecting Us to Death: Women, Pregnancy,

and Clinical Research Trials," *St. Louis Law Journal*, vol. 38 (fall 1993), pp. 136-37.

¹¹² Charo, "Protecting Us to Death," p. 141.

¹¹³ *Ibid.*, p. 144.

¹¹⁴ *Ibid.*, pp. 142-43.

¹¹⁵ Bobinski, "Women and HIV," p. 22, n. 55 (stating that title IX might provide relief, if rejected potential research participants could demonstrate that title IX was intended to protect them, and that they were excluded due to discrimination).

¹¹⁶ 42 U.S.C. §§ 300w-300w-10; 300x-300x-63; 701-710; 8621-8629; 9901-9926 (1994 & Supp. II 1996). These laws contain provisions requiring nondiscrimination on the basis of race, color, national origin, sex, and religion. See chap. 4.

¹¹⁷ USCCR, *Federal Title VI Enforcement*, p. 77.

¹¹⁸ See the Library of Congress, Congressional Research Service, Government Division, *Federalism in the United States: Toward the Third Century an Overview of Trends and Issues*, Rept. No. 89-262 GOV (Apr. 17, 1989), p. 6. See also Arkansas, Louisiana, New Mexico, Oklahoma, and Texas Advisory Committees to the USCCR, *The New Wave of Federalism: Block Granting and Civil Rights in the Southwest Region*, January 1983, p. 3.

alcohol and drug abuse and mental health services, the primary care (repealed in 1988), the maternal and child health services, the social services, and the low-income energy assistance program.¹¹⁹ With the exception of the social services block grant,¹²⁰ each block grant provision in the statute has a section prohibiting discriminatory practices. The nondiscrimination provisions are essentially the same, with a few exceptions. Three of the block grant programs—preventive health and health services, alcohol and drug abuse and mental health services, and maternal and child health services—prohibit discrimination based on race, color, national origin, sex (under title IX), age, and handicap, and provide independent sex and religion nondiscrimination provisions.¹²¹ The community services and low-income home energy assistance block grants prohibit discrimination based on race, color, national origin, sex (under title IX), age, and handicap, but not religion.¹²²

If the Secretary of HHS determines that an entity receiving funds under a program has discriminated, the Secretary must notify the Governor of the State and request that compliance be secured. If such compliance is not secured within a reasonable time (up to 60 days), the Secretary may choose between three enforcement avenues: (1) referring the matter to the Attorney General for imposition of a civil suit; (2) exercising the enforcement powers of title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, or section 504 or the Rehabilitation Act, which includes fund termination procedures; or (3) taking some other action authorized by law.¹²³ The U.S. Attorney General also has enforcement authority under these pro-

visions and may institute a civil action without waiting for a referral from an agency.¹²⁴

Emergency Medical Treatment and Active Labor Act

Four years after passage of the Omnibus Reconciliation Act, in 1985, Congress passed the Emergency Medical Treatment and Active Labor Act (EMTALA) to ensure against private hospitals “dumping” emergency patients, including women in active labor, onto public hospitals because of their inability to pay.¹²⁵ The law became effective on August 1, 1986, and applies to all hospitals that participate in Medicare and that have emergency rooms.¹²⁶ Under the act, if a hospital cannot stabilize a patient, it can transfer the patient to another hospital only if the following conditions are met: (1) the patient requests a transfer, in writing, after being informed of the hospital’s obligations and of the risk of the transfer; (2) the responsible physician certifies in writing that the benefit of the transfer *outweighs* the risk of the transfer; (3) the receiving hospital has available space and qualified personnel for the treatment of the patient and has agreed to accept the patient; (4) the transfer is made with appropriate medical transportation equipment; and (5) the transferring hospital sends all relevant medical reports to the receiving hospital.¹²⁷

Enforcement

EMTALA may be enforced by filing a complaint with the Health Care Financing Admini-

¹¹⁹ Codified as amended, respectively, at 42 U.S.C. §§ 9901–9912; 300w–300w–10; 300x–300x–63; 300y–300y10; 701–709; and 8621–8629 (1994 & Supp. II 1996).

¹²⁰ Final Rules, Block Grant Programs, U.S. Department of Health and Human Services (HHS), Office of the Secretary, 47 Fed. Reg. 29,472, 29, 480 (1982). The Secretary interpreted “other existing laws against discrimination in Federally assisted programs as applying to the Social Services Block Grant.” *Ibid.* Thus, race, color, national origin, sex (only in educational programs), age, and disability are protected from discrimination under this program, but religion is not.

¹²¹ 42 U.S.C. §§ 300w–7(a)(1)–(2); 300x–57(a)(1)–(2); and 708(a)(1)–(2) (1994 & Supp. II 1996).

¹²² 42 U.S.C. §§ 9906(a); and 8625(a) (1994).

¹²³ 42 U.S.C. §§ 300x–7(b)(1)(A)–(C); 300w–7(b); 708(b)(1)–(3); 8625(b)(1)–(3) and 9906(b)(1)–(3) (1994).

¹²⁴ 42 U.S.C. §§ 300x–7(b)(2); 300w–7(c); 708(c); 8625(c) and 9906(c) (1994).

¹²⁵ Section 1867 of the Social Security Act, Aug. 14, 1935, c. 531, as amended by Pub. L. No. 99–272, § 9121 (b), 100 Stat. 164 (1986) (subsequently amended) (codified as amended at 42 U.S.C. § 1395dd (1994)). This U.S. Commission on Civil Rights report will not focus on this statute because it is not enforced by the Office for Civil Rights at HHS.

¹²⁶ 42 U.S.C. § 1395dd(a) (1994).

¹²⁷ 42 U.S.C. § 1395dd(c)(1)–(2) (1994). *See also* Perkins, “Race Discrimination,” p. 380. According to Perkins, “In the years since the antidumping law became effective, consistent government investigations and enforcement efforts have not occurred. A study by the Public Citizen Health Research Group, for example, found that between 1986 and 1991, only 140 hospitals and three physicians were cited for violations, despite an estimated 250,000 dumping incidents each year.” *Ibid.* (citing Public Citizen Health Research Group, “140 Hospitals Named for Patient Dumping Violations,” April 1991, pp. 1–2).

stration (HCFA) or by private suit.¹²⁸ Responsibility for Government enforcement is split between HCFA and the Office of Inspector General (OIG). The OIG may fine hospitals or physicians up to \$50,000 per violation and may cancel physicians' receipt of medicare and medicaid funds for gross or repeated violations.¹²⁹ HCFA may terminate the hospital's medicare and medicaid funds.¹³⁰ In practice, HCFA allows a hospital that has been found in violation 23 days from the date of the confirmed violation to take corrective action.¹³¹ The second avenue of enforcement is private suit. This legal alternative is attractive because it allows the opportunity for a patient to receive damages.¹³² The courts have generally been supportive.¹³³

OCR's Rulemaking and Policy Development for Title VI, Hill-Burton, Title IX, and Block Grants

The development of regulations and policy guidance is a primary means through which civil rights enforcement agencies such as OCR can implement the nondiscrimination provisions of the laws they enforce. It is through regulations and policy guidance that these agencies develop and disseminate approaches to establishing cases of discrimination and guidance on key is-

ssues relating to civil rights enforcement in specific contexts. Taken together, regulations, guidelines,¹³⁴ policies, and investigative guidance should serve to ensure that civil rights enforcement staff implement investigative procedures effectively, fairly, and consistently. In addition, they also should inform recipients of Federal funds of their compliance responsibilities under the law. Finally, guidelines and policies should be available to all beneficiaries of Federal funds.

OCR's mandate requires it to promulgate regulations and policy guidance for several key statutes, including title VI of the Civil Rights Act of 1964,¹³⁵ title IX of the Education Amendments of 1972,¹³⁶ title VI of the Public Health Service Act, known as the Hill-Burton Act,¹³⁷ as well as Omnibus Reconciliation Act of 1981.¹³⁸

DOJ regulations mandate that Federal agencies develop their own regulations and guidelines implementing title VI.¹³⁹ The guidelines

¹²⁸ 42 U.S.C. § 1395dd(d) (1994). See also Joan M. Stieber and Linda J. Spar, "EMTALA Enforcement in the '90s—Enforcement Challenges," *Health Matrix*, vol. 8 (winter 1998), p. 60 (hereafter cited as Stieber and Spar, "EMTALA in the '90s").

¹²⁹ 42 U.S.C. § 1395dd(d)(1) (1994). See also Stieber and Spar, "EMTALA in the '90s," pp. 60–62.

¹³⁰ 42 U.S.C. § 1395cc(b)(2) (1994 & Supp. II 1996). See also Stieber and Spar, "EMTALA in the '90s," pp. 60–62.

¹³¹ HHS, Health Care Financing Administration, *Medicare/Medicaid State Operations Manual*, Part 3412 (Rev. 1/95). See also Stieber and Spar, "EMTALA in the '90s," pp. 60–62.

¹³² 42 U.S.C. § 1395dd(d)(2) (1994). See also Stieber and Spar, "EMTALA in the '90s," pp. 60–62.

¹³³ See, e.g., *Vickers v. Nash General Hosp., Inc.*, 78 F.3d 139, 142 (4th Cir. 1996); *Brooker v. Desert Hosp. Corp.*, 947 F.2d 412, 414 (9th Cir. 1991) (stating that the act did not enumerate specific income or wealth criteria to trigger protection of an individual); *Gatewood v. Washington Healthcare Corp.*, 933 F.2d 1037, 1040 (D.C. Cir. 1991) (remarking that the act did not distinguish between patients with insurance and those without it). But see *Johnson v. University of Chicago Hosps.*, 982 F.2d 230, 233 (7th Cir. 1992) (stating that mere contact between an ambulance and a hospital communication system did not trigger the hospital's EMTALA obligation).

¹³⁴ In the context of Federal nondiscrimination law, guidelines are program-specific rules promulgated by a Federal agency. See U.S. Department of Justice, Coordination and Review Section, "Coordination of Enforcement of Nondiscrimination in Federally Assisted Programs," Guidelines, 28 C.F.R. 42.404 ("Federal agencies shall publish title VI guidelines for each type of program to which they extend financial assistance, where such guidelines would be appropriate to provide detailed information on the requirements of title VI.").

¹³⁵ 42 U.S.C. §§ 2000d to 2000d-7 (1994).

¹³⁶ 20 U.S.C. §§ 1681–1688 (1994).

¹³⁷ 42 U.S.C. §§ 291–291o (1994).

¹³⁸ Codified as amended in scattered sections of 5, 7, 8, 10, 12, 15, 19, 20, 22, 23, 24, 25, 26, 29, 31, 33, 35, 36, 38, 42, 45, 46, 47, 49, 50 U.S.C (1994 & Supp. II 1996)).

¹³⁹ 28 C.F.R. §§ 42.403–404 (1998). Under Executive Order 12250, the U.S. Department of Justice (DOJ) has oversight and coordination responsibility for civil rights enforcement efforts under title VI, title IX, and section 504 of the Rehabilitation Act of 1973. Under Executive Order 12250, the President has delegated overall leadership responsibility for coordinating these efforts to the Attorney General. Exec. Order No. 12250, 3 C.F.R. 298 (1981), reprinted in 42 U.S.C. § 2000d-1 (1994). Within DOJ, the Attorney General has delegated the authority under Executive Order 12250 to the Assistant Attorney General for Civil Rights, who heads the Civil Rights Division (CRD). CRD is the primary entity, among six major civil rights enforcement agencies within the Federal Government, responsible for enforcing Federal statutes prohibiting discrimination on the basis of race, color, sex, disability, religion, and national origin. Merrily Friedlander, chief; Ted Nickens, deputy chief, Programs; Allen Payne, program officer, and Andrew Strojney, deputy chief, Legal; Coordination and Review Section, Civil Rights Division, U.S. Department of Justice, interview in Washing-

are meant to serve as a program-specific supplement to the title VI regulations, for each title VI covered program.¹⁴⁰ DOJ also specifies that agencies should distribute the guidelines to recipients, beneficiaries, compliance officers, and the general public.¹⁴¹

DOJ's Coordination and Review Section (CORS), in the Civil Rights Division, has issued regulations,¹⁴² guidelines,¹⁴³ policy guidance, and investigative guidance. The regulations lay out the responsibilities of Federal agencies on the enforcement of title VI in the following areas: agency regulations and guidelines; public dissemination of title VI information; data and information collection; procedures for determining compliance, including preaward and postaward reviews; complaint procedures; coverage of employment practices under title VI; requirements of State agencies administering continuing State programs; methods of resolving noncompliance; interagency cooperation and delegations; agency staff; and agency title VI enforcement plans.¹⁴⁴

The policy and investigative guidance materials provide more specific rules and procedures in some of the above areas. CORS recently has worked with HHS OCR officials to develop guidance documents on title VI enforcement in welfare reform and limited English proficiency.¹⁴⁵ In addition CORS has published a title VI legal manual¹⁴⁶ and an investigative procedures manual¹⁴⁷ to assist agencies in enforcing titles VI, IX,

section 504, and the nondiscrimination provisions of the block grant programs.

For example, DOJ recently has provided guidelines related to the enforcement of title VI in block grant programs. Referring to the Commission's 1996 title VI report, the DOJ policy guidance states that Federal agencies are ultimately accountable for ensuring nondiscrimination in State administered programs, although they are hindered from tracking the flow of Federal dollars from States to subrecipients (due to States' selection of, and civil rights enforcement authority over, their subrecipients).¹⁴⁸ DOJ explained that its 1999 policy guidance document was issued in response to the U.S. Commission on Civil Rights' recommendation for DOJ to provide guidelines to Federal agencies in enforcing civil rights provisions in the context of State assistance programs.¹⁴⁹

In the 1999 policy guidance, DOJ reiterates a 1982 legal opinion stating that civil rights statutes apply to State programs, unless Congress intended otherwise.¹⁵⁰ The guidance also highlights title VI coordination regulations, including the responsibility for "prompt and vigorous enforcement" of title VI (which rests with the head of each Department administering federally assisted programs) and the responsibility for each State agency administering a federally assisted, continuing program to establish a title VI compliance program for itself and its subrecipients.¹⁵¹ Overall, the document's recommendations relate to how to ensure nondiscrimination in block grant programs. DOJ stresses that the

ton, DC, Jan. 26, 1999, p. 5 (statement of Friedlander) (hereafter cited as CORS interview). See USCCR, *Federal Title VI Enforcement*, pp. 59-66.

¹⁴⁰ 28 C.F.R. § 42.404(a) (1998).

¹⁴¹ 28 C.F.R. § 42.405(a) (1998).

¹⁴² "Coordination of Enforcement of Non-discrimination in Federally Assisted Programs," 28 C.F.R. pt. 42, subpt. F (1998).

¹⁴³ The guidelines, published in 1966, address alternative courses of action available to Federal agencies when they determine that a recipient has violated title VI. 28 C.F.R. § 50.3 (1998).

¹⁴⁴ *Id.* DOJ has also published regulations implementing the nondiscrimination provision of section 504 of the Rehabilitation Act. However, DOJ has not disseminated any regulations implementing title IX of the Education Amendments of 1972.

¹⁴⁵ CORS interview, p. 2.

¹⁴⁶ See U.S. Department of Justice, Civil Rights Division, *Title VI Legal Manual*, September 1998, accessed at <http://www.usdoj.gov/crt/grants_statutes/indexpg.htm> (hereafter cited as DOJ, *Title VI Legal Manual*).

¹⁴⁷ U.S. Department of Justice, Civil Rights Division, *Investigation Procedures Manual for the Investigation and Resolution of Complaints Alleging Violations of Title VI and Other Nondiscrimination Statutes*, September 1998.

¹⁴⁸ Bill Lann Lee, Acting Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, memorandum to Executive Agency Civil Rights Directors, Jan. 28, 1999 (re: enforcement of title VI of the Civil Rights Act of 1964 and related statutes in block grant-type programs) (citing USCCR, *Federal Title VI Enforcement*, p. 155) (hereafter cited as DOJ, Title VI Policy Guidance).

¹⁴⁹ DOJ, Title VI Policy Guidance, p. 2.

¹⁵⁰ *Ibid.*, p. 3 (citing U.S. Department of Justice, Office of Legal Counsel, Memorandum Opinion for the Counsel to the Director, Office of Management and Budget, re: Applicability of Certain Cross-Cutting Statutes to Block Grants Under the Omnibus Budget Reconciliation Act of 1981, p. 113 (1982)).

¹⁵¹ *Ibid.*, pp. 4-5 (citing 28 CFR § 50.3(b) and 28 CFR § 42.410 (1998)).

document's recommendations focus on the responsibilities that a Federal agency mandates for all funding recipients, rather than the responsibilities that can be delegated to primary recipients. DOJ requested that Federal agencies attempt to implement as many of the suggestions as are feasible, considering their particular block grant programs.¹⁵² However, DOJ acknowledges that because of the diversity of block grant and other State programs, it cannot develop a "one-size-fits-all" model that can be useful for all Federal agencies.¹⁵³

General Assessment of OCR's Rulemaking and Policy Development

Overall, the Commission's study of OCR's policy development and implementation indicates that HHS has failed to develop adequate regulations, guidelines, polices, and investigative guidance regarding health care issues. OCR has neither developed adequate new regulations nor updated or revised existing guidance to ensure that recipients understand how to comply with the civil rights mandates it enforces.¹⁵⁴ For example, although block grant programs were created in 1981, OCR never ratified regulations for the implementation of the civil rights provisions in HHS block grant statutes. Aside from

¹⁵² *Ibid.*, p. 6.

¹⁵³ *Ibid.*, p. 23.

¹⁵⁴ DOJ/CORS informed the Commission that it has directed all Federal title VI enforcement agencies not to revise their title VI or title IX regulations. The chief of CORS explained: "That's not HHS' fault. All the title VI agencies have the same exact regulations. We have told them not to update the regulations. There was a decision made several years ago not to touch the title VI [regulations] because [of] backlash, which I agree with. . . Things may be changing very soon, though. . ." (CORS interview, p. 5 (statement of Friedlander)).

Regardless of the earlier decision not to open the title VI regulations for revision, the Commission finds that HHS/OCR needs to make certain changes to its title VI regulations. Moreover, CORS informed the Commission that it has had a title VI model regulation that includes many of the Commission's recommended changes in this report. CORS stated that, basically, it has been waiting for an opportunity to direct the Federal title VI agencies to move forward with changes to their regulations (CORS interview, p. 5 (statement of Friedlander)). The Commission finds that CORS needs to issue the directive to open title VI regulations for revision as soon as possible. Therefore as soon as CORS directs title VI enforcement agencies to go forward with revisions to their regulations, HHS/OCR should implement immediately the necessary changes identified by the Commission.

this failure to effect appropriate implementation of block grant programs, another especially disturbing problem has been the agency's failure to revise its title VI regulations to reflect changes in the law made by the Civil Rights Restoration Act of 1987.¹⁵⁵ This law was a congressional response to a 1984 Supreme Court decision, *Grove City College v. Bell*,¹⁵⁶ that significantly curtailed the broader application of the statute with reference to the scope of the term "programs and activities."

Further, OCR staff have indicated that it should issue more policy guidance. Equal opportunity specialists in Region VII noted that there has been some concern about the lack of formal policy guidance, and the guidance that they do have is often "obsolete."¹⁵⁷ The attorney in that region stated that OCR needs to be more aggressive in developing policy guidance, and such guidance should be published in the *Federal Register*.¹⁵⁸ The regional manager further noted that little training is provided on OCR's policy documents and guidance, and that it is primarily only for OCR staff. The guidance is only written in English and, therefore, cannot be distributed outside the English-speaking community like the OCR fact sheets (which are in several languages).¹⁵⁹

OCR's general failure to use regulations and policies to implement civil rights laws has had a devastating effect on the agency's ability to conduct the thorough, comprehensive enforcement needed to ensure equal access to quality health care in a complex and ever-changing environment. As such, discrimination in health care has been allowed to persist.

OCR policy development for health care, as opposed to human services, has been nearly nonexistent for many years. When HHS was formed in 1980, it lacked individual civil rights policies, precedents, standards, and procedures

¹⁵⁵ 20 U.S.C. §§ 1681, 1687, 1688; 29 U.S.C. §§ 706, 794; 42 U.S.C. §§ 2000d-4a (1994).

¹⁵⁶ 465 U.S. 555 (1984).

¹⁵⁷ Peter Kemp, Jan Ro-Trock, and Maria Smith, equal opportunity specialists, Region VII, OCR, HHS, telephone interview, Feb. 8, 1999, p. 10.

¹⁵⁸ Jean Simonitsch, regional attorney, Region VII, Office of General Counsel, HHS, telephone interview, Feb. 8, 1999, p. 3.

¹⁵⁹ John W. Halverson, regional manager, Region VII, OCR, HHS, telephone interview, Feb. 12, 1999, p. 4 (hereafter cited as Halverson interview).

necessary to operate an effective civil rights enforcement program. Since its creation, HHS has not published any guidelines for title VI, title IX, or section 504 of the Rehabilitation Act, as required by DOJ,¹⁶⁰ nor has it published any guidelines for the Hill-Burton Act.

OCR has an equally scant record on policy development. The vast majority of existing policy guidance relating to health care was disseminated before 1982.¹⁶¹ In recent years, OCR has relied on a case-by-case or ad hoc approach to policy development.¹⁶² Staff have indicated they do not wish to "make a policy in a vacuum," because "it may not do what it was intended to do."¹⁶³ Under this ad hoc approach, OCR policy staff generally wait until an issue presents itself in the context of an actual case, before deciding how the issue should be resolved. Thus, OCR will consider developing policy in cases where

there has been a significant divergence of opinion or confusion among the regions regarding the proper resolution for a particular issue or set of issues.¹⁶⁴ When such disagreement or confusion develops over an issue, OCR may develop guidance to explain or clarify its position.¹⁶⁵ This approach to developing policy reflects a departure from the initial approach used by OCR from 1980 to 1982.¹⁶⁶

The lack of policy development after 1982 may have reflected larger problems with OCR's civil rights enforcement operations. Due to the Secretary's concern about how the Department's civil rights efforts were affected during the 1980s, she charged an intradepartmental team to review HHS' civil rights implementation. With respect to the lack of policy development, the Civil Rights Review Team stated, "One of the most crippling factors that has prevented the Office for Civil Rights and other components of the Department from mounting and sustaining an effective civil rights program has been the absence of clear definitions, or standards, of what constitutes discrimination in the health-care system."¹⁶⁷ Moreover, to the extent that HHS does develop policy, according to the Civil Rights Review Team, such policy is not communicated effectively to OCR staff.¹⁶⁸ The acting director of OCR appeared to agree when he wrote in 1998 that "[t]he various legal and regulatory authorities under which OCR works are varied and disparate. At the moment, the basic statute, case law, regulations, guidance, and other formal policies are not collected and organized for wide scale staff use."¹⁶⁹ Consequently, "the substance of civil rights protection (i.e., what constitutes discrimination and how to discover, prevent, or remedy it) has been largely left undefined and to the discretion of each investigator, manager, reviewer and attorney throughout the organization."¹⁷⁰ HHS OCR's

¹⁶⁰ See 45 C.F.R. pt. 80, app. B (1998). HHS has adopted HEW's guidelines for vocational education programs. *Id.*

¹⁶¹ HHS, OCR, Policy and Special Projects Staff, "Title VI Policy Compendium," vol. I (1984) and vol. II (1985); and HHS, OCR, Policy and Special Projects Staff, "Section 504 Policy Compendium," (undated). These compendia also include policy developed by HEW between 1965 and May 1980. In addition to the policies listed in the policy compendia, OCR has been involved in developing other policies since 1982, including: "Notice to Recipients of Financial Assistance From the HHS (re: application of Federal civil rights laws to persons with AIDS or AIDS-related conditions or those who may be perceived to have AIDS or AIDS-related conditions)," May 30, 1988; "Isolation of AIDS Patients in Health Care Settings" (undated); "Clarification on the Use of Dog Guides by Visually Impaired Persons in Federally Assisted HHS Facilities," Mar. 24, 1988; "The Multi-Ethnic Placement Act of 1994," Apr. 20, 1995; "Inter-ethnic Adoption Provisions of the Small Business Job Protection Act of 1996," June 4, 1997; "Policy Guidance on Investigations of Adoption and Foster Care Placements," May 2, 1989; "Revised Policy Guidance on Preemployment Inquiries," Nov. 3, 1992; "OCR Policy on Consultation with American Indians and Alaska Natives," Apr. 9, 1997; and "Organ Procurement and Transplantation Network Regulation," Apr. 2, 1997. See Thomas E. Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 4 (hereafter cited as Perez letter, June 3, 1999).

¹⁶² Kathleen O'Brien, special assistant to the acting director, OCR, HHS, telephone interview, Jan. 5, 1999, pp. 1-2 (hereafter cited as O'Brien interview).

¹⁶³ Marcella Haynes, director, Office of Policy and Special Projects, Kathleen O'Brien, special assistant to the acting director, OCR, HHS, interview in Washington, DC, Nov. 16, 1998, pp. 12-13 (statement of Haynes) (hereafter cited as PSPS interview).

¹⁶⁴ O'Brien interview, pp. 1-2.

¹⁶⁵ *Ibid.*

¹⁶⁶ HHS, *Report of the Civil Rights Review Team*, September 1993, pp. 1-2 (hereafter cited as HHS, *Review Team Report*). See chap. 3.

¹⁶⁷ HHS, *Review Team Report*, pp. 19-20.

¹⁶⁸ *Ibid.*, p. 10.

¹⁶⁹ David Garrison, acting director, OCR, memorandum to Deputy Secretary, HHS, Aug. 17, 1998, p. 4 (re: OCR management meeting).

¹⁷⁰ *Ibid.*, p. 1.

failure to develop and communicate policies to staff on a host of health care related issues has in all probability resulted in inconsistent and incorrect findings by staff.

OCR still has not begun to address health care issues in policy guidance. Although OCR issued a guidance memorandum in 1998 on patients with limited English proficiency,¹⁷¹ its efforts with respect to other aspects of its mandate, such as civil rights concerns in human services programs (e.g., the Multiethnic Placement Act¹⁷²), appear to have taken precedence over policy guidance on discrimination issues in health care facilities. This is particularly true with title VI enforcement issues. For example, even in the development of its “substantive” compliance manual, OCR has chosen to work on title VI-related enforcement issues last of all.¹⁷³

Definitions and Standards Needed

One purpose for the development of policy guidance, or statements on key objectives, concepts, and terminology relating to civil rights enforcement efforts, is that it provides a means for OCR to communicate more effectively the compliance requirements of the Federal civil rights statutes it enforces to recipients of HHS funds. A statement of OCR’s standards will help the agency to ascertain whether a provider, facility, or managed care organization is in compliance with Federal civil rights laws. Such a statement also can assist recipients to understand more fully the policies and practices they must develop and implement to remain in compliance with Federal civil rights laws.

Equal Access to Quality Health Care

“It is our opinion that access to quality health care is the issue on which the HHS should focus. Both access to and quality of care are equally

important in determining whether a client’s rights have been upheld.”¹⁷⁴

“HHS should focus their title VI and Hill-Burton Act enforcement on health care access ensuring equal access to health care for women and members of racial/ethnic minorities. Failure to comply results in a disproportionate amount of care being provided by some organizations, many times negatively impacted from a financial perspective.”¹⁷⁵

Equal access or equality of opportunity are concepts fundamental to Congress’ purpose in enacting civil rights laws such as title VI and title IX. Standards evaluating whether a recipient is providing all of its patients equal access to the health care services must address inequities in both access to and quality of health care that have historically existed and continue on the basis of race, ethnicity, and gender in the health care system. As one commentator has noted:

If equitable access means, or is defined as, the actual receipt of the quality and quantity of services needed, then access in America has been inequitable. Many individuals receive different health care (both quantity and quality) based on characteristics other than medical need. The care received by the wealthy is different than the care received by the poor; the care received by European Americans is different than the care received by ethnic Americans; and the care received by men is different than the care received by women.¹⁷⁶

These are the very inequities that Federal civil rights provisions such as title VI and the community assurance provision of the Hill-Burton Act’s implementing regulations seek to redress.

The need to improve access to quality health services is acknowledged in HHS’ objectives for

¹⁷¹ See HHS, OCR, “Guidance Memorandum: Title VI Prohibition Against National Origin Discrimination—Persons with Limited English Proficiency,” Jan. 29, 1998 (hereafter cited as OCR, “Guidance Memorandum on Limited English Proficiency”).

¹⁷² Pub. L. No. 103–382, 108 Stat. 3518 (codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997)).

¹⁷³ See David Garrison, acting director, OCR, HHS, and Omar Guerrero, deputy director, OCR, HHS, interview in Washington, DC, Nov. 23, 1998, p. 3 (hereafter cited as Garrison and Guerrero interview).

¹⁷⁴ William Gregory, executive director, Excelsior Youth Centers, Inc., Aurora, CO, letter to Mireille Zieseniss, USCCR, Feb. 7, 1999 (re: HHS investigation), p. 2.

¹⁷⁵ Cindy Noa, administrative director, Patient Care, Carle Clinic Association, Urbana, IL, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 25, 1999 (re: HHS investigation).

¹⁷⁶ Vernellia R. Randall, “Does Clinton’s Health Care Reform Proposal Ensure Equality of Health Care for Ethnic Americans and the Poor?” *Brooklyn Law Review*, vol. 60 (spring 1994), p. 169 (citations omitted) (hereafter cited as Randall, “Clinton’s Health Care Proposal”).

improving health under its Healthy People 2010 initiative. According to HHS:

Many of the persisting disparities in health outcomes across population groups reflect problems of access within a continuum of care that includes preventive services, primary care, emergency services, and long-term and rehabilitative care. Additionally, these four elements of the health care system represent critical components of the interface between public health and clinical medicine.¹⁷⁷

HHS relies on the definition of access developed by the Institute of Medicine, "the timely use of personal health services to achieve the best possible health outcomes."¹⁷⁸ The Institute of Medicine notes, however:

No matter how generally efficacious a particular health service may be, a good health outcome cannot always be guaranteed. The most important consideration is whether people have the opportunity for a good outcome—especially in those instances in which medical care can make a difference. When those opportunities are systematically denied to groups in society, there is an access problem that needs to be addressed.¹⁷⁹

Quality of care is an equally important element to the issue of equal access to care. According to one advocacy group, improving the quality of health care will ultimately lower the costs of and increase access to health care.¹⁸⁰ According to the executive director of the National Coalition on Health Care, "[E]very American, including every minority, should be guaranteed adequate access to quality health care."¹⁸¹ To do this, it is important to create and maintain effective public clinics that are available to all, thus providing an alternative to "the emergency room problem" in which those without health insur-

ance are forced to use the emergency room as their primary source of health care.¹⁸²

OCR does not have clear definitions and standards to use in civil rights enforcement activities to determine whether health care providers are offering equal access to health care services. Further, when analyzing whether an individual has equal access to care, OCR must also focus on the *quality of care* provided. Currently, there is no single, adequate definition of equal access to quality health care. The lack of a defined benchmark for equal access to quality of care is a barrier to civil rights enforcement faced by OCR and other defenders of civil rights statutes. As such, it is imperative that OCR clearly define the concept of equal access to quality health care, and provide guidance to its staff in investigating charges of the denial of access.

In developing a definition of equal access to quality health care, OCR should consider that the term "access" is "a broad and often vaguely defined concept" that has encompassed a number of variables, including the supply and availability of health care providers, health insurance coverage, and identification and removal of barriers to access.¹⁸³ Further, the problem of defining access is complicated by difficulties in measuring access, particularly the standards for evaluating whether health care facilities are admitting and treating patients fairly and competently.¹⁸⁴ In particular, the word "access" is somewhat ambiguous, since it incorporates so many different possible elements.

OCR has taken the first steps toward developing a policy statement defining equal access. OCR's *Case Resolution Manual* states, for example, that OCR's mission is to "promote and ensure that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination." However, OCR does not attempt to define clearly the meaning of the term "equal access" to health care, even though this is a term that may be open to widely different interpretations.

¹⁸² Ibid.

¹⁸³ Center for Studying Health System Change, "Access to Health Care: Bridging the Gap Between Policy and Research," issue brief, no. 8 (April 1997), p. 1.

¹⁸⁴ Ibid., pp. 1-2.

¹⁷⁷ HHS, Office of Public Health and Science, *Healthy People 2010 Objectives: Draft for Public Comment*, Sept. 15, 1998, Access to Quality Health Services, p. 10-3 (hereafter cited as HHS, *Healthy People 2010*).

¹⁷⁸ Institute of Medicine, Committee on Monitoring Access to Personal Health Care Services, *Access to Health Care in America* (Washington, DC: National Academy Press, 1993), pp. 4, 33.

¹⁷⁹ Ibid., p. 4.

¹⁸⁰ Margaret Rhodes, executive director, National Coalition on Health Care, telephone interview, July 2, 1998, p. 2.

¹⁸¹ Ibid.

Without some form of guidance, to both its own staff and recipients and beneficiaries of HHS funding, it is impossible to know what OCR is referring to when it states that its mission is to provide "equal access." It is, therefore, very difficult to know what exactly the agency seeks to find when it evaluates whether a recipient is complying with Federal civil rights mandates, particularly what efforts a health care provider must undertake to ensure that it is in compliance. Further, absent an adequate definition of both "equal access" and "quality health care," OCR staff may not realize that the quality of health care is an important civil rights issue.¹⁸⁵

Imagining the efforts OCR might undertake and the elements it could include in a policy statement defining "equal access" in the health care context provides a helpful means of focusing the debate over what exactly such a statement should contain. It seems an appropriate first step in developing such a policy statement would be to review the work of the many commentators who have written on equal access to health care as a civil right. Based on the ideas presented in their work, a policy statement defining "equal access" in health care might contain an opening section illustrating the inequities in gaining access to health care that have confronted Americans who are members of racial and ethnic minorities and women, both historically and in the present. It also might contain a section on how Congress has sought to remove these inequities by enacting statutes such as title VI and title IX and the nondiscrimination provisions in block grant statutes. In addition, such a policy statement might contain a discussion on the authority Congress has given OCR to promulgate regulations under title VI, Hill-Burton, and title IX. OCR should refer to the provisions in these regulations that define discrimination.

This policy statement also might contain a discussion identifying the principal forms of dis-

crimination on the basis of race, color, and national origin in the health care industry. Specifically, it should observe that the *effect* of differential treatment based on relative ability to pay has been that racial/ethnic minorities, as the segment within American society least able to afford health care services, continue to experience difficulty in obtaining access to health care commensurate with that provided to white Americans. One commentator's observations are particularly appropriate in conveying the importance of this issue. He stated:

A national health system that conditions health care on the ability to pay will inevitably discriminate against racial minorities. As almost any school child knows, there is a strong correlation in America between race and poverty. Minorities are also much more likely to be represented among the ranks of the uninsured. Why then should we be surprised at racial disparities in access to health care? How could it be otherwise?¹⁸⁶

This policy statement might discuss the myriad of other policies and practices engaged in by health care providers that create discrimination on the basis of race, color, or national origin and explain *why* specific practices result in discrimination. For example, it might explain that such factors as distance, travel time and other transportation difficulties, excessive waiting times in emergency rooms, and inadequate means of addressing language barriers all may constitute discrimination and can result in denial of equal access to quality health care.¹⁸⁷ Therefore, the only legitimate determinant of who receives health care and the manner in which it is delivered should be the need for service. All other determinants cannot play a role without potentially implicating title VI regulatory provisions and presenting possible civil rights violations under the statute or its regulations. As one commentator observed, "Health care access may be considered equitable, therefore, when the primary determinant of

¹⁸⁵ In interviews with Commission staff, several OCR staff noted that complaints concerning the quality of care and appropriate care were not necessarily within OCR's jurisdiction. See, e.g., Peter Kemp, Jan Ro-Trock, and Maria Smith, equal opportunity specialists/investigators, Region VII, OCR, HHS, telephone interview, Feb. 8, 1999, p. 5 (hereafter cited as OCR Region VII EOS interview); Roger Geer, regional attorney, Region VI, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 3, 1999, p. 5 (hereafter cited as Geer interview); OCR Region X EOS interview, pp. 6-7 (statement of Plymouth).

¹⁸⁶ Gordon Bonnyman, Jr., "Unmasking Jim Crow," *Journal of Health Politics, Policy, and Law*, vol. 18, no. 4 (winter 1993), p. 872.

¹⁸⁷ Jane W. Peterson, Yvonne M. Sterling, and DeLois P. Weekes, "Access to Health Care: Perspectives of African American Families with Chronically Ill Children," *Family Community Health*, vol. 19, no. 4 (1997), p. 64 (citing R. Evans, "Asthma among minority children," *Chest*, vol. 101, no. 6 (1992), pp. 368S-71S).

one's use of basic health care services is one's level of need for health care, rather than one's wealth, geographical location, or other factors."¹⁸⁸

To provide equal access to quality health care, a health care service provider must first remove all discriminatory policies and practices that lead to denial of equal access to quality health care. In defining a standard for evaluating whether a service provider is delivering quality health care equitably, this policy statement also should seek to imbue the term "equal access" with a precisely defined practical meaning that can help OCR to establish more clearly at least the broad parameters of the requirements a health care provider must meet to show compliance.

Equal Access

Based on a wide-ranging review of health care related literature, laws, and research studies, the Commission has identified three broad areas that, taken together, comprise the "universe" of the Nation's health care system: health care services delivery, health care financing, and medical research. The policy statement should stipulate that, in order to ensure equality of access in health care the following must be addressed: health care service delivery or treatment must be provided in an effective, high-quality manner for everyone; services must be made available to all patients without regard to their method of payment; and all research efforts must be inclusive and aimed at achieving results that will make such research effective in addressing health issues for everyone, regardless of race or sex. Therefore, any definition of equal access should contain the following elements: (1) quality of health care received must not be affected by the recipient's race, ethnicity, sex, or method of payment; (2) assurance that *everyone* has the availability of appropriate financing; and (3) inclusive, effective research.

Using the broad perspective outlined above as a baseline, the definition of equal access then must establish specific criteria to be used in

¹⁸⁸ Steven P. Wallace, Vilma Enriquez-Haass, and Kyriakos Markides, "The Consequences of Color-Blind Health Policy for Older Racial and Ethnic Minorities," *Stanford Law and Policy Review*, vol. 9 (spring 1998), p. 330 (hereafter cited as Wallace et al., "Color-Blind Health Policy").

evaluating whether health care services are being provided to ensure that the elements above are present. One regional OCR attorney stated that the criteria for assessing equality of access in health care regardless of race, color, national origin, and sex should resemble those used in the disability discrimination context under section 504 of the Rehabilitation Act of 1973, where such a standard already exists. He stated, "I think the standard in 504 is that you need auxiliary aids to have substantially the same kind of service as someone else. I think that in equal access, everyone has to have 'substantially equal access' to the basics and maybe even beyond the basics."¹⁸⁹

Consistent with this line of thought, another OCR attorney stated that equal access must be measured on the basis of whether everyone has been provided the same "unrestricted acquisition, use, or entry accorded all persons notwithstanding, race, gender, disability, etc."¹⁹⁰ A regional manager who has also been a regional attorney stated that equal access is making sure that everybody who utilizes a facility gets the same opportunity to participate in and obtain services. He noted that the problem is assessing what the standard is supposed to be and what groups are receiving adequate services.¹⁹¹

An attorney from Region IV said:

For a facility to ensure equal access, it must provide similar types of services to all individuals, apply the same criteria to all when determining eligibility, and apply the same standards to all patients when deciding a particular service or procedure . . . Opening a facility door, charging the same fee, and speaking English to all individuals does not constitute equal access. However, these theoretical measures of equality are not sufficient on the policy level. The standards must be implemented so that the results of the access are there, and that minority (or disabled or LEP) individuals enjoy the services to the same ex-

¹⁸⁹ Bill Rhinehart, attorney, Region III, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 24, 1999, p. 8 (hereafter cited as Rhinehart interview).

¹⁹⁰ Velveta Golightly-Howell, attorney, Region VIII, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 11, 1999, p. 5 (hereafter cited as Golightly-Howell interview).

¹⁹¹ Ira Pollack, regional manager, Region IX, OCR, HHS, telephone interview, Feb. 17, 1999, p. 10 (hereafter cited as Pollack interview).

tent as their nonminority (or nondisabled or English-speaking) peers.¹⁹²

The attorney in Region III stated that to measure equal access, it is necessary to look at relevant medical standards. Certain protocols and procedures should be followed by physicians; it should be investigated whether these have been strayed from and, if so, what the motivation was. According to this attorney, these things need to be analyzed on a case-by-case basis.¹⁹³

Overall, OCR's regional attorneys seem to agree that, in establishing criteria to evaluate whether equal access has been afforded, the focus must be on consistency in the means of determining eligibility, the medical standards applied for conducting specific procedures, and the manner in which services are provided. Moreover, they seemed to agree that any policy on equal access is useless unless OCR has a means for actually observing whether recipients are providing their services in accordance with policy recommendations. At least one attorney said that any policy on equal access would not be effective unless recipients have specific examples of how to provide equal access in different "real-world" contexts.¹⁹⁴ Taken together, the comments of these experienced civil rights attorneys perhaps provide a starting point for the development of OCR policy guidelines that would both define "equal access" and indicate the criteria and standards OCR would use to measure whether a given recipient is providing services to all patients in an equal manner.

Quality of Care

OCR must be concerned not only with equal access to health care, but with equal access to *quality* health care. OCR staff agreed that it is difficult to assess the issue of quality of health care. For example, Region VIII staff stated that in the Denver area the hospital that treats minority patients is known as one of the best; however, hospitals in the suburbs may not be so

¹⁹² Roosevelt Freeman, attorney, Region IV, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 10, 1999, p. 5 (hereafter cited as Freeman interview).

¹⁹³ Morales interview, p. 5.

¹⁹⁴ Stewart Graham, chief counsel, Region I, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 22, 1999, p. 11 (hereafter cited as Graham interview); Freeman interview, p. 5.

willing to accept medicaid.¹⁹⁵ As such, the quality of health care provided to medicaid recipients is not consistent across the region. Thus, a standard "civil rights enforcement" definition of quality health care is needed that can be applied during compliance reviews and investigations.

Legal commentators have stated that the definition of quality of health care must be "particularize[d] . . . to describe acceptable medical procedures, and institutional structures and processes."¹⁹⁶ According to these commentators:

The structural characteristics of the settings in which care takes place have a propensity to influence the process of care so that its quality is diminished or enhanced. Similarly, changes in the process of care, including variations in its quality, will influence the effect of care on health status, broadly defined.¹⁹⁷

Thus, in defining quality health care, one must include standards and criteria for acceptable practices, as well as a recognition of the need for documentation of health care decisions and the physician's responsibility for clinical decisions.¹⁹⁸ Further, any assessment of quality of care also must include an analysis of medical outcomes (including the health status of the patient), the actual services performed for the patient, and the characteristics of the resources used to treat the patient (including the training of the medical personnel).¹⁹⁹ This definition must be integrated

¹⁹⁵ Andrea Oliver, Jean Lovato, Doris Genko, equal opportunity specialists, Region VIII, OCR, HHS, telephone interview, Feb. 9, 1999, p. 6 (hereafter cited as OCR Region VIII EOS interview).

¹⁹⁶ Barry R. Furrow, Sandra H. Johnson, Timothy S. Jost, and Robert L. Schwartz, *Liability and Quality Issues in Health Care* (St. Paul, MN: West Publishing Co., 1991), p. 18.

¹⁹⁷ *Ibid.*, p. 20.

¹⁹⁸ *Ibid.* These authors note, "In the medical procession, as in other processions, standards develop in a complicated way involving the interaction of leaders of the procession, professional journals and meetings, and networks of colleagues. Neither the Food and Drug Administration, the National Institutes of Health, the Department of Health and Human Services, nor state licensing boards have had much to do with shaping medical practice." *Ibid.*, p. 36.

¹⁹⁹ Marc A. Rodwin, "Patient Accountability and Quality of Care: Lessons from Medical Consumerism and the Patients' Rights, Women's Health and Disability Rights Movements," *American Journal of Law and Medicine*, vol. 20 (1994), p. 148 (hereafter cited as Rodwin, "Accountability and Quality of Care") (citing Avedis Donabedian, "Criteria and Standards for Quality Assessment and Monitoring," *Quality Review Bulletin*, March 1986, pp. 99-108).

with the provision stated in the civil rights statutes, regulations, guidelines, and policies that cover equal access to health care services or treatment.

OCR staff attempted to define quality of care for the Commission. The Region VIII staff defined quality of care as the level of care received based on general medical practices.²⁰⁰ The attorney in Region VIII defined quality of care as "the nature or type of care afforded patients in the provision of services."²⁰¹ The Region III attorney stated that for quality of care to be "substantially the same," patients must have similar access to facilities as well as doctors and necessary specialists:

For example, if poor folks are not referred to a cardiologist whereas other folks are going to have that angioplasty and they are going to pay for it and they have top notch insurance, they go and they get referred to the cardiologist; that may have some disparate impact and implications based on race and national origin. I think it is those kinds of things that go into quality of care, but I would say again, substantially the same access to the same types of care.²⁰²

Any definition of quality health care must recognize that there are several aspects to quality of care. According to one expert on quality in health care:

The search for a definition of quality can usefully begin with what is perhaps the simplest complete module of care: the management by a physician, or any other primary practitioner, of a clearly definable episode of illness in a given patient. It is possible to divide this management into two domains: the technical and the interpersonal. Technical care is the application of the science and technology of medicine, and of the other health sciences, to the management of a personal health problem. Its accompaniment is the management of the social and psychological interaction between client and practitioner. The first of these has been called the science of medicine and the second is art.²⁰³

Commentators have also remarked on the importance of cultural competency in providing

quality care. These authors stress the importance of providers being able to competently interact with individuals from different backgrounds and racial and ethnic groups.²⁰⁴ Cultural differences, such as misunderstanding customs, mistrust, and language barriers, all have an effect on the quality of care one receives.²⁰⁵

Thus, for access to health care to be equal, all Americans must be provided with the same quality of health care. OCR must consider these concerns when evaluating whether or not someone has been discriminated against in the provision of health care services. To do this, OCR must have a clear, precise definition of what it means when it uses the term "equal access." Any definition of equal access developed by OCR should include "quality health care" as one of its elements. In turn, OCR should be careful to incorporate all factors that contribute to equal access to quality health care services or treatment, such as cultural competency and appropriate care.

Appropriate Care

According to one commentator, one aspect of institutional racism in the health care context is "the occurrence of racial disparities in type of services ordered and in the provision of medical treatment itself [which is] well-documented in studies done on cardiology, cardiac surgery, kidney disease, organ transplantation, internal medicine and obstetrics."²⁰⁶ Types of treatment and the appropriateness of medical practices are elements of quality of care. To assess whether an individual received equal access to quality care, it is important to determine if appropriate care was provided to that patient. However, when asked if they had a working definition of the term "appropriate care" several OCR staff indicated that they make no determination of what appropriate care is, and that such an assessment

²⁰⁴ Nicole Lurie, "Studying Access to Care in Managed Care Environments," *Health Services Research*, vol. 32, no. 5 (December 1997), p. 691.

²⁰⁵ Sally Kohn, "Dismantling Sociocultural Barriers to Care," *Healthcare Forum Journal*, May/June 1995, p. 32.

²⁰⁶ Vernellia R. Randall, "Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans," *Health Matrix*, vol. 3 (1993), p. 160. See USCCR, *The Health Care Challenge*, vol. I, chaps. 2-3, for a detailed discussion of differences in medical treatments by race, ethnicity, and sex.

²⁰⁰ OCR Region VIII EOS interview, p. 7.

²⁰¹ Golightly-Howell interview, p. 5.

²⁰² Rhinehart interview, p. 9.

²⁰³ Avedis Donabedian, *The Definition of Quality and Approaches to its Assessment* (Ann Arbor, MI: Health Administration Press, 1980), p. 4.

may not even be in their jurisdiction.²⁰⁷ For example, one equal opportunity specialist stated that OCR does not get involved in cases about “the types of treatment one person received over another,” “whether procedure A versus procedure B, or a less costly versus more costly procedure, was provided to a particular person,” or “arguments between doctors and patients,” all of which he considers to be strictly quality of care matters and outside the purview of OCR, unless discrimination (under a statute enforced by HHS) by a health care provider or facility was alleged by the complainant.²⁰⁸ Indeed, several staff noted the inability to obtain the medical expertise needed to challenge a recipient’s medically related rationale, suggesting that OCR was not equipped to make such determinations.²⁰⁹

Nonetheless, appropriate care, as well as quality of care and equal access, are concepts that are crucial in determining the existence of discrimination. OCR staff must have an understanding of and apply such concepts if they are to assess whether individuals have been discriminated against in the health care context. Discrimination occurs not only in the denial of services, but also in the provision of inferior, inadequate, or inappropriate health care services or medical practices.

Discussions of quality of care and appropriateness of care are at the heart of efforts to reform health care.²¹⁰ For example, in proposed legislation in the Senate the concepts of appropriate care and medical necessity are at issue. The Patients’ Bill of Rights would allow patients to appeal a health plan’s denial of services.²¹¹ The bill also would prohibit managed care plans from penalizing members for paying out-of-

pocket for mental health services when such services have been denied by the plan.²¹² Such a prohibition is necessary to ensure that patients receive appropriate care, regardless of their health plans’ efforts to save money and avoid lawsuits.²¹³

OCR equal opportunity specialists and regional attorneys have made suggestions as to the criteria they would use in creating a means of evaluating whether equal access to care, in terms of quality and appropriate care, is being provided. For example, two regional attorneys offered criteria specifically relating to ensuring across-the-board consistency in the application of the medical standards applied by health care professionals. One attorney stated:

[I would look at] the relevant medical standards . . . with a particular disease. In most of the cases I have dealt with I know that there are certain protocols and certain procedures that are followed by doctors when they are confronted with a patient with a particular affliction or disease. I would look to see whether or not these doctors have strayed from the generally recognized procedures when dealing with that disease. I would look to see what the motivation is if indeed they have strayed from a particular procedure.²¹⁴

In keeping with this focus on consistency in applying standards of care, another attorney stated that when she sees the term “appropriate care,” the first thing she associates with the term is what type of care does this person need—acute care, rehabilitated care, custodial care. According to this attorney, appropriate care includes not only the level of care needed but the setting in which care is provided (such as in a nursing home). She noted that, in terms of civil rights, it is necessary to make sure that access to appro-

²⁰⁷ OCR Region VII EOS interview, p. 5; Geer interview, p. 5. However, Region III staff noted that when a complaint alleges the quality of care is different, staff are obligated to investigate and determine whether or not there is discriminatory quality of care. OCR Region III EOS interview, p. 4. Nonetheless, it is evident that there is no clear method across the regions of assessing quality and appropriateness of care.

²⁰⁸ OCR Region X EOS interview, pp. 6–7 (statement of Plymouth).

²⁰⁹ OCR Region VII EOS interview, p. 5; Freeman interview, pp. 10–11; Graham interview, p. 15. See chap. 4.

²¹⁰ See chap. 6 for a discussion of health care reform.

²¹¹ S. 326, 106th Cong., § 503 (1999). See generally Karen Foerstel, “Debate on Managed Care Legislation Diverges Along Familiar Lines,” *Congressional Quarterly Weekly*, Mar. 20, 1999, p. 702.

²¹² Foerstel, “Debate on Managed Care,” p. 702. According to Foerstel, “Some plans threaten to drop coverage for their patients who continue to seek treatment at their own cost after it has been denied. The plans fear if the treatment proves effective, they could be sued for denying appropriate care.” *Ibid.*

²¹³ This prohibition should be extended to *all* forms of health care, not just mental health services.

²¹⁴ Fernando Morales, attorney, Region II, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 3, 1999, p. 16 (hereafter cited as Morales interview).

appropriate care is not based on race or any other discriminatory factor.²¹⁵

Another attorney stated that he would define appropriate care as that care which a medical professional would judge to be needed to sustain the health of the individual.²¹⁶ Similarly, staff in Region VIII stated that appropriate care is care provided in accordance with general medical practices.²¹⁷ The Region VIII attorney defined appropriate care as "care which is suitable or consistent with the symptomology of and warranted by the patient's condition."²¹⁸

In developing guidance on appropriate care, OCR should turn to medical experts and research on appropriate medical procedures and practices. For example, the associate general counsel in the Office of General Counsel, Civil Rights Division, stated that research done in the context of managed care would be useful in determining appropriate care and appropriate outcomes. He stated that the growth of managed care has resulted in much research being done to develop the criteria for which treatments are most appropriate for certain conditions, as well as standards of diagnosis and other issues related to appropriate care.²¹⁹

OCR staff need to better understand the standards applied in the medical profession in regards to appropriate care. OCR, with the guidance of medical experts and civil rights experts (internal and external), should prepare a policy document that discusses appropriate health care delivery or treatment within the context of civil rights enforcement.²²⁰ This document should identify the medical standards applied to different health conditions, such as the standard for the appropriate treatment of diabetes and breast cancer. Such guidance would ensure that OCR staff do not improperly dismiss cases that, on the

surface, appear to be a question of the type or quality of services received, rather than a charge of discrimination.

Remedial Measures

Despite OCR's lack of policy development and guidance during the 1990s, the agency has taken some important steps to reduce the specter of incorrect findings in its compliance reviews and complaint investigations. For example, OCR has assigned a regional civil rights attorney to each of its 10 offices.²²¹ However based upon the Commission's review, it appears that either the regional OCR offices are not making adequate use of the legal expertise provided to them or the legal staff do not have appropriate expertise or experience in civil rights enforcement relative to discriminatory issues. Possibly, a combination of both problems is limiting the regional offices in dealing with systemic, difficult, and novel health care issues. Qualified compliance officers are needed to appropriately handle such issues. Rather than increasing legal staff, OCR should concentrate on training its staff in legal and civil rights enforcement issues related to health care.

OCR is attempting to address some of the deficiencies in its civil rights enforcement program and its policy guidance materials by developing a "substantive" compliance manual. When finished, this manual is supposed to provide comprehensive guidance to OCR regional staff and recipients on specific issues relating to each of the statutes OCR enforces.²²² OCR hopes that this will enhance the agency's ability to conduct the thorough, comprehensive civil rights enforcement needed to ensure equal access to quality health care.

Unfortunately, title VI and title IX appear to be somewhat "forgotten" statutes by the agency. OCR's deputy director stated that the bulk of OCR's work on the manual has focused on section 504, the ADA, and the Hill-Burton Act.²²³

²¹⁵ Ellen Miyasato, attorney, Region X, Office of General Counsel, Civil Rights Division, HHS, telephone interview, Feb. 2, 1999, pp. 6-7 (hereafter cited as Miyasato interview).

²¹⁶ Geer interview, p. 3.

²¹⁷ OCR Region VIII EOS interview, p. 7.

²¹⁸ Golightly-Howell interview, p. 4.

²¹⁹ George Lyon, associate general counsel, Civil Rights Division, Office of General Counsel, HHS, interview in Washington, DC, Dec. 22, 1998, p. 6 (hereafter cited as OGC interview).

²²⁰ The development of a definition of appropriate care and guidelines for assessing appropriate care could be done in conjunction with OCR's efforts to define equal access to quality health care.

²²¹ USCCR, *Federal Title VI Enforcement*, p. 225.

²²² Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy associate deputy director, OCR, HHS, interview in Washington, DC, Oct. 16, 1998, p. 5 (hereafter cited as O'Brien and Mackey interview). According to OCR staff, the manual will also be available to beneficiaries. See Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 1.

²²³ Garrison and Guerrero interview, p. 3.

He stated that the manual eventually would include a chapter on title VI, but that title VI currently is not the focus of the manual.²²⁴ He stated further that it would be more difficult and would take more time to develop a thorough policy analysis and discussion on title VI since it remains an “abstract” area, with little case law to use as guidance.²²⁵ As of late 1998, no work on title VI issues had begun.²²⁶ However, staff intend to include treatments of such topics as managed care, nursing home segregation, and medical redlining.²²⁷ Considering that there is so little guidance on title VI, and that it is a very important aspect of OCR’s civil rights enforcement responsibilities, it would seem appropriate to focus more attention, sooner rather than later, on addressing title VI-related issues in the manual.

Title VI: Rulemaking and Policy Development

Title VI of the Civil Rights Act of 1964 is the broadest, potentially most versatile tool available to OCR in ensuring nondiscrimination and equal access to quality health care for minorities. It is for this reason that much of the Commission’s review of OCR’s regulations, guidelines, and policy focuses on OCR’s efforts to develop regulations and policy guidance to implement title VI. Also, this statute has served as a blueprint for later civil rights laws and provisions, such as title IX and the community assurance provision of the Hill-Burton regulations. As such, congressional intent in creating title VI and judicial interpretation of the statute’s mandate informs any analysis of efforts to implement the other civil rights laws for which the agency is responsible.

As intended by Congress, courts have construed title VI to mandate that agencies promulgate rules and regulations that establish en-

forcement policy and procedures and define the discriminatory practices prohibited.²²⁸ Courts have determined that the responsibility for defining what title VI forbids and the form of compliance under title VI is committed to the Federal agency.²²⁹ Courts have held that an agency’s determination of what constitutes discrimination is entitled to great weight;²³⁰ and agency regula-

²²⁸ See, e.g., *Alabama NAACP State Conference of Branches v. Wallace*, 269 F. Supp. 346, 351–52 (M.D. Ala. 1967) (holding that title VI manifests clear intent to limit the power of the Federal agencies and to require action pursuant to definite rules, regulations, or guidelines so that State and local authorities may be able to understand, in advance of enforcement, the enforcement policy and to conform voluntarily their actions to those rules, regulations, and guidelines).

²²⁹ See, e.g., *Women’s Equity Action League v. Cavazos*, 906 F.2d 742, 748 (D.C. Cir. 1990). However, although an agency is empowered to issue regulations that facilitate enforcement of title VI, it may not adopt a standard for discrimination that squarely conflicts with the standard legislated by Congress or adopted by the courts. See, e.g., *Bryan v. Koch*, 492 F. Supp. 212, 234 (S.D.N.Y. 1980), *aff’d*, 627 F.2d 612 (2d Cir. 1980). In addition, agency action concerning racial discrimination is reviewable. Congress explicitly intended that agencies’ findings, in some cases, be subject to judicial scrutiny. See, e.g., *Southern Christian Leadership Conf. v. Connolly*, 331 F. Supp. 940, 945 (E.D. Mich. 1971). The standard of review to be applied is that provided for under the Administrative Procedure Act, 5 U.S.C. §§ 701–706 (1994). The court must set aside action found to be “arbitrary and capricious,” an abuse of discretion, or otherwise not in accordance with the law; or action taken contrary to various constitutional, statutory, or procedural requirements. *Id.* § 706(2)(A) – (D) (1994). In cases in which agency action is based upon an adjudicatory or rulemaking hearing, agency action must also be set aside if the action is not supported by “substantial evidence,” or if, after a trial *de novo*, the action was “unwarranted by the fact.” *Id.* § 706(2)(E), (F). See, e.g., *NAACP v. Wilmington Med. Ctr.*, 453 F. Supp. 280, 303 (D. Del. 1978), *later proceeding*, 453 F. Supp. 330 (D. Del. 1978) (denying plaintiffs related but separate claim challenging the constitutionality of the HEW issued regulations whereby the Secretary approved relocation of hospital), *remanded and reaffirmed*, 657 F.2d 1322 (3rd Cir. 1981).

²³⁰ See, e.g., *Chevron U.S.A., Inc. v. Natural Resources Defense Council, Inc.*, 467 U.S. 837, 844 (1984) (stating “[w]e have long recognized that considerable weight should be accorded to an executive department’s construction of a statutory scheme it is entrusted to administer, and the principle of deference to administrative interpretations”). See also *Udall v. Tallman*, 380 U.S. 1, 16 (1965) (holding that where an administrative agency is charged with the interpretation and enforcement of a statute by Congress, its interpretations are entitled to considerable weight by the courts); *Raney v. Board of Educ. of Gould Sch. Dist.*, 381 F.2d 252, 255 (8th Cir. 1967), *rev’d on other grounds*, 391 U.S. 443 (1968); *Blackshear Residents Org. v. Housing Auth. of Austin*, 347 F. Supp. 1138, 1146 (W.D. Texas 1971); *Whit-*

²²⁴ *Ibid.*

²²⁵ *Ibid.*

²²⁶ *Ibid.* In July 1999, OCR informed the Commission that it had contracted with an expert from George Washington University to assist in the development of the title VI chapter. Thomas Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 7, 1999 (re: health care report), addendum, p. 3.

²²⁷ Perez letter, June 3, 1999, enclosure, “Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions,” p. 1.

tions have been upheld as valid interpretations of title VI, unless inconsistent with the purposes of the statute.²³¹ Such regulations have been held by the courts to have the force and effect of law.²³²

Deficiencies in the Title VI Regulations

OCR's title VI regulations were not revised when HHS became a separate Department in 1980,²³³ so they are essentially identical to the Department of Education's title VI regulations. HHS is not alone among the Federal title VI enforcement agencies in duplicating the Department of Education's title VI regulations. DOJ/CORS has recommended that the title VI enforcement agencies refrain from changing their title VI regulations.²³⁴

Nonetheless, the failure to make key revisions in the regulations since 1980 is critical because it signifies that HHS has hardly developed its title VI enforcement program since its creation in 1980. In addition, certain sections of the HHS title VI regulations pertain specifically to educational institutions and are, therefore, apparently irrelevant to HHS activities.²³⁵ An en-

tire appendix to the regulations naming specific kinds of Federal financial assistance to which the regulations apply is duplicated from the original title VI regulations of the former Department of Health, Education, and Welfare. As a result, there are items relating to education funding rather than health care.²³⁶ Considering the bifurcation of HEW occurred nearly 20 years ago, it seems appropriate for HHS to revise this appendix by removing items for recipients funded by the Department of Education.

The Commission found in its 1996 report on title VI enforcement other significant weaknesses in the title VI regulations that HHS has failed to address.²³⁷ For example, HHS has not updated the regulations to reflect the amendment to title VI created by the Civil Rights Restoration Act of 1987.²³⁸ The act amended the definition of "programs or activities" to restore broad coverage for title VI's nondiscrimination provision.²³⁹

The act defined the term "program or activity" in title VI and title IX to ensure that the nondiscrimination provisions of these statutes extended beyond the individual program or activity being funded to prohibit discrimination throughout entire agencies or institutions if any part receives Federal financial assistance.²⁴⁰ In addition, the legislative history indicates that the act retained the fund termination remedy for cases in which discrimination is "pinpointed" to a specific federally funded program, or when the federally assisted program is "infected" by dis-

tenberg v. Greenville County Sch. Dist., 298 F. Supp. 784, 789 (D.S.C. 1969).

²³¹ See, e.g., *Guardians v. Civil Service Commission*, 463 U.S. 582, 592 (1983) (citing *Zenith Radio Corp. v. United States*, 437 U.S. 443, 450 (1978)); *Lau v. Nichols*, 414 U.S. 569-571 (1974); *Blackshear Residents Org. v. Housing Auth. of Austin*, 347 F. Supp. 1138, 1146 (W.D. Texas 1971).

²³² See, e.g., *Guardians v. Civil Service Commission*, 463 U.S. 582, 591-93 (1983) (disparate impact discrimination exists under the title VI regulations independent of the title VI statute itself, which only prohibits acts of intentional discrimination); *Blackshear Residents Org.*, 347 F. Supp. at 1146; *Macon County Bd. of Ed.*, 270 F. Supp. at 862; *Alabama NAACP State Conference of Branches*, 269 F. Supp. at 352. That force of law has been found to include requiring recipients to sign adequate assurances of compliance, *Gardner v. Alabama*, 385 F.2d 804, 815-16 (5th Cir. 1967), cert. denied, 389 U.S. 1046 (1968) (extending title VI coverage to all programs operated through an assisted facility); *Flanagan v. President & Directors of Georgetown College*, 417 F. Supp. 377, 383-84 (D. D.C. 1976); requiring recipients to overcome affirmatively the effects of prior discrimination, *Soria v. Oxnard Sch. Dist. Bd. of Trustees*, 386 F. Supp. 539, 544-45 (C.D. Cal. 1974); and, requiring prompt investigation of complaints, *Brown v. Weinberger*, 417 F. Supp. 1215, 1220-21 (D.D.C. 1976).

²³³ See *id.* HHS title VI regulations (formerly HEW's) were last revised in 1973.

²³⁴ CORS interview, p. 5 (statement of Friedlander).

²³⁵ For example, the regulations contain a provision requiring assurances of compliance from elementary and second-

ary schools, and a section that provides an illustrative example pertaining to construction aid and general support for elementary and secondary schools. See, e.g., 45 C.F.R. §§ 80.4(c), 80.5(b) (1998).

²³⁶ For example, the items listed in the appendix include "[l]oans for acquisition of equipment for academic subjects, and for minor remodeling"; "[c]onstruction of facilities for institutions of higher education"; and "[s]chool construction in federally-affected and in major disaster areas." See 45 C.F.R. § 80 app. A (1998).

²³⁷ The provision amending title VI of the Civil Rights Act is codified at 42 U.S.C. § 2000d-4a (1994). See also *Federal Title VI Enforcement*, pp. 223-24.

²³⁸ See 42 U.S.C. § 2000d-4a (1994).

²³⁹ U.S. Congress, Senate, Committee on Labor and Human Resources, Civil Rights Restoration Act of 1987, 100th Cong., 2d sess., S. Rep. No. 64, p. 1, reprinted in 1988 U.S.C.C.A.N. 3.

²⁴⁰ See 42 U.S.C. § 2000d-4a (1994). See also 1988 U.S.C.C.A.N. 3, 6.

crimination elsewhere in the operations of the recipient.²⁴¹

The title VI regulations also do not specifically address procedures for block grant programs. In 1986 HHS proposed a rule on nondiscrimination requirements applicable to block grants,²⁴² but that rule has never been issued in final form. The proposed rule specifies that the HHS block grant programs are covered by previous nondiscrimination statutes, including title VI.²⁴³ It requires HHS to notify the chief executive officer, or Governor, of the State receiving the block grants when HHS has found a funding recipient in noncompliance.²⁴⁴ The Governor must be afforded 60 days to secure a voluntary compliance agreement.²⁴⁵ If he or she fails to do so, HHS “will effect compliance in according with the procedures outlined in section 80.8 of the HHS title VI regulations.”²⁴⁶

In 1991 HHS developed an internal draft regulation on title VI national origin discrimination against persons with limited English proficiency.²⁴⁷ As late as 1993, the agency identified this draft regulation as a proposed rule in its Proposed Regulatory Agenda published in the *Federal Register*.²⁴⁸ In 1994 the regulation was withdrawn from the agenda.²⁴⁹ Since then, OCR has not issued a Notice of Proposed Rulemaking or taken any other steps to further the process of developing a final rule on limited English proficiency.

Overall, the HHS title VI regulations:

- Allow a finding based on disparate impact.²⁵⁰
- Prohibit employment discrimination in programs whose purpose is not to provide em-

²⁴¹ See 1988 U.S.C.A.N. 3, 22.

²⁴² 51 Fed. Reg. 2,806 (1986). HHS has also developed a proposed rule regarding national origin discrimination against persons with limited English proficiency. See 58 Fed. Reg. 56,294 (1993) (unified agenda).

²⁴³ 51 Fed. Reg. 2,806.

²⁴⁴ *Id.*

²⁴⁵ *Id.* § 92.4.

²⁴⁶ *Id.*

²⁴⁷ HHS, OCR, Proposed LEP Regulation, July 1991 (unofficial document).

²⁴⁸ 58 Fed. Reg. 56,294 (1993).

²⁴⁹ See 59 Fed. Reg. 20,312, 20,328 (1994).

²⁵⁰ 45 C.F.R. § 80.3(b)(2)–(3) (1998). See this chapter, “Defining Prohibited Discriminatory Practices,” for a discussion of disparate impact.

ployment when such discrimination causes discrimination in the program.²⁵¹

- Include the requirement that all State recipients of Federal funds develop “methods of administration.”²⁵²
- Broadly permit, but do not require affirmative action, except in programs that have previously discriminated.²⁵³

The regulations provide some guidance on discriminatory action and other key enforcement issues from a general perspective. However, as explained earlier in this section, they do not address specific areas of major importance, such as the changes to title VI made by the Civil Rights Restoration Act of 1987²⁵⁴ and the nondiscrimination requirements of the block grant statutes.

Deficiencies in Title VI Policy and Guideline Development

Since its creation as a separate entity, HHS has not published any title VI guidelines for its federally assisted programs as required by DOJ.²⁵⁵ Consequently, HHS staff and recipients and participants in HHS programs may lack critical information about the title VI compliance requirements of those programs. HHS’ title VI staff and funding recipients lack detailed information on how to conduct title VI implementation, compliance, and enforcement procedures relative to each of the specific grant programs HHS administers.

Beyond OCR’s failure to publish formal guidelines, the agency’s efforts to develop title VI policy guidance, particularly in the health care context, have been limited and largely inadequate for many years. OCR’s “high-water mark” for title VI policy development appears to have occurred in the early 1980s. During the 2-year period following HHS’ creation in 1980, there seems to have been a period of significant policy development, although the extent to

²⁵¹ *Id.* § 80.3(c)(3).

²⁵² *Id.* § 80.4(b)(2).

²⁵³ *Id.* § 80.3(b)(6)(i)–(ii).

²⁵⁴ 20 U.S.C. §§ 1681, 1687, 1688; 29 U.S.C. §§ 706, 794; 42 U.S.C. §§ 2000d–4a (1994)

²⁵⁵ See *id.* pt. 80, App. B (1998). Like DOE, HHS has adopted HEW’s guidelines for vocational education programs. *Id.* However these guidelines pertain to programs that are under HHS and not under DOE.

which these policies were disseminated among recipients and staff is indeterminable.

OCR has compiled and indexed this guidance in several compendia of policy letters and memoranda developed during 1980–1982, as well as those issued before HHS' creation. These compendia show that between 1980 and 1982, the agency developed several policy documents relating to title VI in the health care context.²⁵⁶ So few title VI policy guidance documents have been issued since that time, so there has been little need to create a third volume to the compendium.

Defining Prohibited Discriminatory Practices *Establishing Cases of Discrimination*

OCR's title VI regulations provide several approaches to establishing the presence of discrimination, depending on the type of case and issues involved.²⁵⁷ Generally, OCR relies on two theories of discrimination when investigating complaints and conducting compliance reviews: disparate treatment and disparate impact.²⁵⁸ Historically, courts and OCR have applied to title VI cases the burden of proof tests associated with these theories that developed under title VII of the Civil Rights Act of 1964.²⁵⁹

Disparate treatment, also known as intentional discrimination, occurs when the recipient²⁶⁰ of Federal funds takes an adverse action against the complainant because of the complainant's race, color, or national origin.²⁶¹ Disparate (or adverse) impact occurs when a recipient's facially neutral policy adversely affects one group of a particular race, color, or national origin more than another, without a legitimate jus-

tification.²⁶² Disparate impact cases do not require proof of the recipient's discriminatory motive.²⁶³

OCR's title VI regulations specifically define prohibited forms of discrimination.²⁶⁴ Under the regulations, prohibited action incorporates both disparate treatment and disparate impact. Some examples of specifically named prohibited actions include:

²⁵⁶ See *id.*, at 335–36 n.15 (establishing title VII business necessity analysis). See also 45 C.F.R. § 80.3(b)(2)–(3) (1998) (expressly prohibiting adverse impact). The U.S. Department of Justice also has stated that title VII cases “may shed light on an analysis concerning the applicability of title VI to a given situation” with respect to disparate impact. See DOJ, *Title VI Legal Manual*, p. 2.

The “business necessity” standard, applied in title VII employment discrimination cases, has been analogized to apply in other contexts. See this chapter, “Defining Discriminatory Practices Prohibited,” for more discussion on this standard as applied to title VI. In title VI cases involving disparate impact in the health care context, one court has required defendants to show a “health care” or medical necessity. See *Latimore v. Contra Costa County*, No. C 94–1257, slip op. at 20 (N.D. Cal. Aug. 1, 1994) (stating that the defendant's burden is to show that the disparate impact was required by necessity . . . or that the challenged conduct has a manifest relationship to . . . health care objectives), *preliminary injunction dissolved*, *Latimore v. Contra Costa County*, No. C 94–1257 (N.D. Cal. Mar. 27, 1995), *dissolution affd.*, 77 F.3d 489 (9th Cir. Feb. 1, 1996) (table case format), 1996 U.S. App. LEXIS 3524 (No. 95–15886); *NAACP v. Med. Ctr., Inc.*, 657 F.2d 1322, 1354 (3d Cir. 1981) (en banc) (stating that the heart of the issue in the case was whether the disputed policy “with its disproportionately adverse effects” was “unnecessary”).

However, the “health care” necessity standard has not been applied uniformly in the title VI health care context. See *Bryan v. Koch*, 627 F.2d 612, 618 (2d Cir. 1980) (finding that recipient's decision to close a hospital was reasonably related to legitimate need for efficient operation of the city's hospital system).

²⁶³ *International Bhd. of Teamsters v. United States*, 431 U.S. at 335–36, n.15. Under the title VI regulations, claimants may show that they have been discriminated against based on adverse impact in a variety of ways. For example, with respect to “determining the site or locations of a facilities [sic]” the regulations state that “an applicant or recipient may not make selections with the effect of excluding individuals from . . . any programs to which this regulations applies on the ground of race, color, or national origin.” The regulations further state that recipients or applicants may not make selections with the “purpose or effect of defeating or substantially impairing the accomplishment of the objectives of the Act.” 45 C.F.R. § 80.3(b)(3) (1998).

²⁶⁴ 45 C.F.R. § 80.3(b)(1) (1998).

²⁵⁶ These are composed largely of letters or memoranda from OCR headquarters to regional office heads. Among the issues addressed are hospital relocations and methods of administration for health care recipients. To the extent these documents are relevant to the discussion, they are mentioned below.

²⁵⁷ See 45 C.F.R. § 80.3(b)(3)(1)–(3) and § 80.3(c) (1998).

²⁵⁸ *Id.* § 80.3(b)(1)–(2).

²⁵⁹ Pub. L. No. 88–352, title VII, § 701, 78 Stat. 253 (codified as amended at 2000e–2000e–17 (1994)).

²⁶⁰ For purposes of this discussion, “recipient” represents any and all possible respondents to a title VI complaint, such as subrecipients.

²⁶¹ *International Bhd. of Teamsters v. United States*, 431 U.S. 324 (1977).

- Denying an individual any service, financial aid, or other benefit provided under the program.²⁶⁵
- Providing any service, financial aid, or other benefit to an individual which is different, or provided in a different manner, from that provided to others under the program.²⁶⁶
- Treating an individual differently from others in determining whether he satisfies any admission, enrollment, quota, eligibility, membership or other requirement or condition which individuals must meet in order to be provided any service, financial aid, or other benefit provided under the program.²⁶⁷
- Utilizing criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin.²⁶⁸
- In determining the site or location of a facilities, making selections with the effect of excluding individuals from, denying them the benefits of, or subjecting them to discrimination under any programs to which this regulation applies, on the ground of race, color, or national origin; or with the purpose or effect of defeating or substantially impairing the accomplishment of the objectives of the Act or this regulation.²⁶⁹

Defining Disparate Impact Discrimination

*"[T]he disparate impact situation remains a current and significant problem in modern health care . . . [However], in most cases [in the health care context], courts have allowed defendants to justify disparate impact with minimal evidence."*²⁷⁰

²⁶⁵ *Id.* § 80.3(b)(1)(i).

²⁶⁶ *Id.* § 80.3(b)(1)(ii).

²⁶⁷ *Id.* § 80.3(b)(1)(v).

²⁶⁸ *Id.* § 80.3(b)(2).

²⁶⁹ *Id.* § 80.3(b)(3).

²⁷⁰ Amy Jurevic, "Disparate Impact Under Title VI: Discrimination, By Any Other Name, Will Still Have the Same Impact," *Saint Louis University Public Law Review*, vol. XV, no. 2 (1996), p. 241.

As HHS' Civil Rights Review Team found in 1993, "the substance of civil rights protection (i.e., what constitutes discrimination and how to discover, prevent, or remedy it) has been largely left undefined and to the discretion of each investigator, manager, reviewer and attorney throughout the organization."²⁷¹ OCR has not addressed sufficiently in regulations or policy guidance two important issues: (1) the means of establishing the element of harm in disparate impact cases, and (2) the standard recipients must meet in justifying policies or practices that result in disparate impact for minority individuals and communities. The insufficiency of OCR's guidance on these two issues derives principally from the lack of updated policy guidance.

OCR's title VI regulations are clear in establishing disparate impact as a means of making a case of discrimination under title VI.²⁷² However, OCR does not discuss in regulations or policy the applicable standards for title VI disparate impact cases in the health care context. Such guidance could benefit OCR investigative staff and recipients and beneficiaries. For example, it could provide numerous illustrative examples and fact patterns relating to these issues in different contexts, including the managed care industry, the medicare and medicaid programs, and hospital relocations. Such updated guidance also would provide OCR the opportunity to reinforce and further clarify its policy positions on the issues of establishing harm and assessing recipients' claims in disparate impact cases.

OCR has also not discussed relevant court decisions that inform an analysis of the requirements needed to show harm or the appropriate standards for assessing defendants' claims in disparate impact cases. Such guidance would benefit OCR investigative staff by providing a

²⁷¹ HHS, *Review Team Report*, p. 1.

²⁷² 45 C.F.R. § 80.3(b)(2)-(3) (1998). As one commentator has noted, the primary obstacle faced by title VI claimants in hospital relocation and closure cases is "no longer the adoption of appropriate statutory language, the promulgation of regulations to prohibit disparate effects, nor judicial recognition of such standards. Applicable anti-discrimination provisions now clearly require demonstrations of disparate effects and not evidence of discriminatory intent." Marianne L. Engelman Lado, "Breaking the Barriers to Health Care: A Discussion of the Role of Civil Rights Litigation and the Relationship Between Burdens of Proof and the Experience of Denial," *Brooklyn Law Review*, vol. 60 (spring 1994), p. 266 (hereafter cited as Lado, "Breaking the Barriers").

current, detailed, and comprehensive discussion of the legal underpinnings, particularly relevant statutory and case law from the past 20 years, for the standards on which OCR relies in such enforcement activities as compliance reviews and complaint investigations.

Establishing the Element of Harm

In disparate impact cases, some courts have increased the requirements for showing harm. An early case that "raised the bar" for plaintiffs is *Bryan v. Koch*,²⁷³ where the plaintiffs protested the closing of a hospital in the Harlem section of New York City.²⁷⁴ The hospital, Sydenham, served a 98 percent minority patient population.²⁷⁵ The plaintiffs argued that the hospital closure created a disparate impact on them, in violation of title VI, because the nearest municipal hospital remaining open in Harlem lacked capacity for the Sydenham patients and that the voluntary hospitals would not treat them, particularly uninsured patients.²⁷⁶ The court dismissed the plaintiffs' claims, finding that closure of Sydenham Hospital would "affect a comparatively small number of persons," that "adequate alternative treatment appears available for most, if not all, of these persons," and that "any inconvenience due to travel changes in this case do not rise to the level of harm necessary to enlist the equitable powers of the court."²⁷⁷

More recently, in *Mussington v. St. Lukes-Roosevelt Hospital Center*,²⁷⁸ the plaintiffs argued that the decision of St. Lukes-Roosevelt Hospital Center to move services from its St. Luke's site to its Roosevelt site would create an adverse impact on minorities in the community surrounding St. Lukes Hospital.²⁷⁹ The court did not reach the merits of the case because the plaintiffs failed to meet the statutory deadline for filing the case.²⁸⁰ However, the court did offer

an opinion as to the case. It opined that moving certain services would have an impact on the plaintiffs,²⁸¹ but also stated that the decision to relocate "does not in itself amount to a discriminatory act."²⁸²

The unwillingness of these courts to accept the barriers created by health care policies and practices as evidence of disparate impact discrimination ignores the difficulties of minority communities in gaining access to quality health care. As one commentator has observed, "The courts have tended to dismiss the hardships of travel to a distant location for the purpose of obtaining health care as mere inconveniences."²⁸³ However, OCR regional attorneys believe that factors such as access to transportation and differing hospital policies on insurance provide sufficient evidence of harm to require a recipient to present evidence showing that its actions were necessary and that there were no less discriminatory alternatives.²⁸⁴

For example, one OCR attorney stated that she believes the argument of increased travel time is definitely a valid argument for establishing harm. However, she does not think the courts "are ready to go that far yet."²⁸⁵ She noted that many courts today and for at least the last decade have not welcomed disparate impact claims in the health care context, and that as a result, plaintiffs and OCR complainants can have a very difficult time establishing discrimination.²⁸⁶ Overall, as commentators and OCR civil rights attorneys agree, these decisions have increased requirements for showing harm under a disparate impact theory of discrimination, thereby making it more difficult for plaintiffs in such cases to establish the harm required to prove a case of disparate impact discrimination under title VI.

In writing about this judicial trend toward devaluing the significance of barriers to health care access, one commentator, a health care pol-

²⁷³ 492 F. Supp. 212, 237 (S.D.N.Y. 1980), *aff'd*, 627 F.2d 612 (2d Cir. 1980).

²⁷⁴ *Id.* at 614.

²⁷⁵ *Id.*

²⁷⁶ 627 F. 2d at 617 n.2.

²⁷⁷ 492 F. Supp. at 237.

²⁷⁸ 824 F. Supp. 427 (S.D.N.Y. 1993), *aff'd*, 18 F.3d 1033 (2d Cir. 1994) (*per curiam*).

²⁷⁹ *Id.* at 429.

²⁸⁰ *Id.* at 433.

²⁸¹ *Id.* at 431.

²⁸² *Id.*

²⁸³ David Barton Smith, "Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards," *Journal of Health Politics, Policy & Law*, vol. 23, no. 1 (February 1998).

²⁸⁴ Golightly-Howell interview, p. 4; Morales interview, pp. 17-18.

²⁸⁵ Golightly-Howell interview, p. 4.

²⁸⁶ *Ibid.*, p. 4.

icy expert with extensive litigation experience, has described it as a “mismatch between the experiences of our clients, who must contend with barriers of access, and the unwillingness of courts to acknowledge these experiences and to accord them weight.”²⁸⁷ This commentator has observed two issues that OCR and plaintiffs’ attorneys must address to demonstrate harm more effectively in adverse impact cases and prove noncompliance under the regulations.²⁸⁸ The first is a measure for determining whether the recipient’s action represented the least discriminatory alternative. Second, the effect of the movement or closure of services on the ability of a population to obtain needed medical care should be incorporated into the court’s analysis of harm.²⁸⁹ Developing these measures requires the expertise of medical, social science, and other professional research staff.

For example, medical geography may be used to analyze the accuracy with which planners predict changes in utilization that may result from the closing of specific hospitals. For example, with respect to the closing of the St. Lukes hospital in the *Mussington* case, the earlier work of medical geographers involved in the *Sydenham* case revealed that patients who would have used the northern Manhattan St. Lukes hospital would not easily travel to the Roosevelt Division downtown.²⁹⁰ Since Sydenham was located only blocks away from St. Lukes, the Sydenham study was instructive for the St. Lukes case.²⁹¹ The medical geographer’s study found that Sydenham patients moved to familiar nearby facilities rather than distributing as had been forecasted.²⁹² Fewer Sydenham patients than expected had moved to hospitals located to the east or south, and fewer than expected had moved to Roosevelt.²⁹³ This work validated the concerns of the plaintiffs in *Bryan* that the loss of beds at the Sydenham site would in fact result in limited access to health care for the affected minority community.²⁹⁴

²⁸⁷ Lado, “Breaking the Barriers,” p. 266.

²⁸⁸ Ibid.

²⁸⁹ Ibid.

²⁹⁰ Ibid.

²⁹¹ Ibid., p. 263, n. 72.

²⁹² Ibid.

²⁹³ Ibid.

²⁹⁴ Ibid., p. 264.

Other research in the field of medical geography has yielded the following significant findings: distance from home to regular source of care is a relatively more important factor for inner-city residents than for suburban residents; proximity to daily activity areas is a significant determinant for the poor, whereas more mobile suburbanites, who are accustomed to traveling relatively long distances for work or shopping, can incorporate a stop for health services into their routine trips;²⁹⁵ the inner-city poor expend more time in the journey for health care, though going shorter distances, and are, thus, at a disadvantage when seeking care;²⁹⁶ the spatial distribution of medical care is an important determinant of utilization; and few if any members of lower or middle-class African American communities studied access suburban medical care.²⁹⁷

OCR staff have stated that they use the expertise of social science and other professional research staff working in various agency elements of HHS to assess alternative means to actions that are creating a disparate impact.²⁹⁸ As shown with the example of medical geography research, this expertise can provide empirical evidence necessary to strengthen an argument that a claimant has experienced harm. Such interaction is crucial to the development of specific criteria to address these means of more effectively demonstrating harm in adverse impact cases. Such interaction is equally important in applying these criteria to establish noncompliance in specific OCR cases involving title VI funding recipients. OCR does not have any social science or other scientific experts on its staff and relies on this outside expertise on an ad hoc ba-

²⁹⁵ Ibid., p. 266 n. 85 (citing Wilber M. Gesler and Melinda S. Meade, “Locational and Population Factors in Health Care-Seeking Behavior in Savannah, Georgia,” *Health Services Research*, vol. 23 (1988), pp. 443, 444, 456–59).

²⁹⁶ Ibid. (citing Gary W. Shannon et al., “Time and Distance: The Journey for Medical Care,” *International Journal of Health Services*, vol. 3 (1983), p. 243).

²⁹⁷ Ibid. (citing Gary W. Shannon et al., “The Search for Medical Care: An Exploration of Urban Black Behavior,” *International Journal of Health Services*, vol. 8 (1978), p. 530).

²⁹⁸ PSPS interview, p. 10. Ms. O’Brien stated that OCR relies “on experts in the Department to help assess alternative means. For instance, in the St. Luke’s case, we talked to architectural experts. They couldn’t convert a hospital because they couldn’t decide how to provide the services given the technology and physical structure of the building. Each case is different, and the decision depends on how the standards and guidelines are laid out.” Ibid.

sis. If it does not implement a plan to recruit scientific and medical experts on its own staff, at a minimum, OCR should develop a formal policy to guide its interaction with experts from other agency elements.

"Health Care Necessity" Standard

Another ambiguity that relates to the definition of impact discrimination is the standard used to determine whether a recipient's discriminatory practice is legally justifiable. After a plaintiff has shown that a policy or practice of a recipient affects minorities adversely and disproportionately, the recipient must justify that policy or practice to the court. Unfortunately, the title VI case law on this justification framework is scant.²⁹⁹ Only 3 Federal court cases—two involving circuit courts of appeals, one involving a Federal district court—have addressed the issue in the health care context, and they articulated different standards: the circuit courts referred to a "legitimate justification" standard and the district court, a more stringent "necessity" standard.³⁰⁰ The absence of a cohesive body of case law establishing a justification standard has prevented recipients from fully comprehending their responsibilities under title VI. OCR has not provided guidance on this standard.

Because the fundamental purposes of civil rights statutes that support a disparate impact theory are similar, courts have often looked to such other statutes for assistance in interpreting title VI issues.³⁰¹ Both of the circuit courts of appeals interpreting title VI in the health care context referred to the title VII evidentiary frame-

work imposed upon plaintiffs and defendants.³⁰² A brief description of this framework will illustrate the procedural fundamentals particular to impact cases.³⁰³ To make a case of adverse impact discrimination, the plaintiff must introduce statistical evidence showing that a policy or practice of an employer disproportionately affected members of a protected class.³⁰⁴ If the plaintiff is able to establish this, the burden of persuasion then shifts to the defendant to justify the challenged policy or practice by proving that it has a "manifest relationship to the employment in question."³⁰⁵ This showing is called the "business necessity" standard.³⁰⁶ If the defendant meets its burden of showing that the policy or practice is necessary, the burden of persuasion then shifts back to the plaintiff to prove that there are less discriminatory alternatives that would also serve the employer's legitimate objective of employing qualified individuals.³⁰⁷ Although title VI courts have disagreed as to how to define the defendant's objective, and the extent to which the policy or practice must further that objective, the essential structure of the title VII burden-shifting framework has been adopted in the title VI context.³⁰⁸

²⁹⁹ See *Bryan v. Koch*, 627 F.2d at 618–19; *NAACP v. Med. Ctr., Inc.*, 657 F.2d at 1322.

³⁰⁰ However, one of the courts explicitly acknowledged that the title VII framework does not mesh seamlessly into the complex web of administrative circumstances that might arise in a title VI case. See *Bryan v. Koch*, 627 F.2d at 618–20.

³⁰¹ See *Griggs v. Duke Power*, 401 U.S. 424 (1971). This initial argument brought by the plaintiff is called the "prima facie case," and represents the minimum amount of evidence required in order for the plaintiff to go forward in court. A prima facie case must contain elements that, if the defendant were to put on no evidence, would allow the plaintiff to prevail. If the plaintiff is unable to establish the prima facie case, the case is dismissed.

³⁰² *Griggs*, 401 U.S. at 431 (1971). See also the Civil Rights Act of 1991, Pub. L. No. 102–166, §§ 105(a), 106, 107(a), 108, 105 Stat. 1074–1076, 42 U.S.C. 2000e–2(k) (1994) (codifying the business necessity evidentiary framework that was created in *Griggs* and *Albemarle Paper Co. v. Moody*, 422 U.S. 405 (1975)).

³⁰³ See *Griggs*, 401 U.S., at 431 ("[t]he touchstone is business necessity"). The analogous term in the health care context would be "health care necessity." If the term were applied using a strict analogy, the defendant's policy or practice would have to be manifestly related to a legitimate health care objective, rather than to a business objective such as hiring qualified employees.

³⁰⁴ *Albemarle Paper Co. v. Moody*, 422 U.S. 405, 425 (1975).

³⁰⁵ See, e.g., *Larry P. by Lucille P. v. Riles*, 793 F.2d 969 (9th Cir. 1986) (applying the title VII burden-shifting framework

²⁹⁹ There have been only two Federal circuit court cases that addressed the necessary elements of a defendant's justification in title VI impact discrimination in the health care context. See, e.g., *Bryan v. Koch*, 627 F.2d 612 (2d Cir. 1980); *NAACP v. Wilmington Med. Ctr.*, 657 F.2d 1322 (3d Cir. 1981). See also *Watson*, *Reinvigorating Title VI*, p. 964.

³⁰⁰ Compare *Bryan v. Koch*, 627 F.2d at 612 (applying a legitimate justification standard); *NAACP v. Wilmington Med. Ctr.*, 657 F.2d at 1322 (articulating a legitimate justification standard in dicta) with *Latimore v. Contra Costa County*, No. C 94–1257, slip op. at 20 (N.D. Cal. Aug. 1, 1994) (applying the necessity standard articulated in *Larry P. by Lucille P. v. Riles*, 793 F.2d 969, 982 (9th Cir. 1986), a ninth circuit disparate impact case in the education context).

³⁰¹ See, e.g., *NAACP v. Med. Ctr.*, 657 F.2d at 1322 (condoning the district court's use of title VIII impact standards); *Bryan v. Koch*, 627 F.2d at 618–19 (referring to title VII as "instructive" for title VI impact cases).

The few courts that have addressed the defendant's evidentiary burden in title VI health care cases have not applied very stringent standards. For example, the second circuit, refusing to incorporate the "less discriminatory alternatives" prong into the title VI health care analysis, has applied a mere rational relationship test requiring the defendant only to show that it had a legitimate justification for its policies and practices.³⁰⁹ The third circuit also adopted a somewhat lax standard, requiring the defendant only to "go forward with evidence that [the challenged policy would] in theory and practice serve a legitimate bona fide interest, and show that no alternative course of action could be adopted that would enable that interest to be served with less discriminatory impact."³¹⁰ The weakness of this standard is underscored by a ninth circuit decision interpreting title VI in the education context. The ninth circuit interpreted the title VI regulations to require that: (1) the plaintiff has the initial burden of demonstrating that a policy has a "discriminatory impact" after which (2) the burden shifts to the defendants to show that its policy was *necessary*.³¹¹ There appears no clear resolution in the case law as to whether the proper standard is mere justification or whether it must rise to the level of a medical or health care "necessity," although leading decisions such as *Bryan v. Koch* have

to a title VI case in the education context). See also Watson, "Reinvigorating Title VI," p. 955; Stan Dorn, Michael A. Dowell, and Jane Perkins, "Anti-discrimination Provisions and Health Care Access: New Slants on Old Approaches," *Clearinghouse Review*, special issue (summer 1986), pp. 439-53 ("[e]mployment discrimination cases under title VII of the Civil Rights Act, 42 U.S. §§ 2000e et seq., have precedential value for title VI cases" (p. 44, n. 61). These commentators also stated that title VI health care "[a]dvocates should cite helpful title VII cases from their circuits holding that defendants have a heavy burden in proving 'business necessity' for practices shown to have a disparate impact on minorities." *Ibid*).

³⁰⁹ See, e.g., *Bryan v. Koch*, 627 F.2d at 623 (holding that in the title VI health care context a policy with a disparate impact can be justified merely by showing the policy is rationally related to a legitimate need).

³¹⁰ *NAACP v. Wilmington Med. Ctr.*, 657 F.2d 1322, 1336 (3d Cir. 1981) (quoting 491 *NAACP v. Wilmington Med. Ctr.*, 491 F. Supp. 290, 315-16 (D.Del. 1980)). It should be noted that this case was decided prior to the Civil Rights Act of 1991, and its reinstatement of the defendant's burden was one of persuasion, rather than production.

³¹¹ *Larry P*, 793 F.2d at 982 (emphasis added).

applied the lower, mere "justification" standard.³¹²

OCR has not clarified its position on applicable standards in disparate impact cases in many years. This is the case even though one high-level attorney in the Office of General Counsel's Civil Rights Division, which provides legal guidance to OCR, has stated that this issue is "certainly a relevant title VI issue and . . . certainly a relevant issue for the civil rights operation in the Department of Health and Human Services."³¹³ In particular, with respect to both standards for establishing harm and the appropriate standard recipients must meet in title VI disparate impact cases, OCR staff have stated that they rely on policy guidance developed some "15 or 20" years ago.³¹⁴

This guidance, issued in January 1981, was a letter from OCR's deputy director of Program Development written in response to an inquiry from OCR's Region II.³¹⁵ It is not clear to what extent this document was disseminated among other regional staffs. The guidance states that a recipient will violate title VI if its action "will have a disproportionate adverse effect and is not necessary to further a legitimate objective."³¹⁶ However, the letter does not reference, describe, or explain the case law on which this standard is based. This weakens the document's effectiveness as policy or investigative guidance because it does not provide investigative staff with a clear and complete understanding of the analyses they are conducting in compliance reviews and complaint investigations, particularly in

³¹² *Compare* *Latimore v. Contra Costa County*, No. C 94-1257, slip op. at 20 (N.D. Cal. Aug. 1, 1994) (granting a preliminary injunction based on a finding that plaintiffs had made a prima facie showing of discriminatory impact and the defendants had failed to rebut the case with a showing that their policy was a necessity) *with* *Bryan v. Koch*, 627 F.2d 612, 617 (2d Cir. 1980) (requiring a justification for disputed action but not a showing of necessity).

³¹³ OGC interview, transcript, p. 13.

³¹⁴ PSPS interview, pp. 9-10. Ms. Haynes stated, "We have a memorandum that we have been operating under for over 15 to 20 years on hospital closure/relocation, describing for the regions how they would go about dealing with those situations." *Ibid*.

³¹⁵ See David F. Chavkin, deputy director for Program Development, OCR, HHS, letter to Alan R. Momohara, acting regional director, OCR, HHS, Jan. 19, 1981 (re: hospital reductions, closures and relocations) (hereafter cited as Chavkin letter).

³¹⁶ Chavkin letter, p. 2.

cases involving hospital closures and relocations. Further, this document does not contain *any* discussion of applicable (at the time) case law to show the underpinnings of compliance standards used in analyzing data obtained from compliance review and complaint investigations. In addition, this guidance does not provide specific examples of the application of this standard in different contexts, such as hospital relocations, managed care, limited English proficiency, medical redlining, and “dumping” cases. Consequently, it is not a thorough, comprehensive review and analysis of these standards.

Also, given that this document is outdated, it cannot address the evolution in the law, including both statutory and case law, relating to title VI disparate impact. For example, the definition of “business necessity” set forth by Congress in the Civil Rights Act of 1991,³¹⁷ which amended title VII of the Civil Rights Act of 1964, informs an analysis of disparate impact under title VI.³¹⁸ Moreover, the evolution of case law on this issue during the past 20 years has been one of confusion rather than consensus. As explained above, courts have applied different standards, from a requirement that a defendant present only a mere justification for policies creating a disparate impact, to a showing of medical or health care “necessity.” Given this lack of consensus, at a minimum, new guidance on the issue addressing the differing standards and clarifying OCR’s position would be highly beneficial to investigative staff.

According to OCR staff, in 1998 the agency sponsored a training session on applicable standards in title VI disparate impact cases.³¹⁹ In addition, OCR has provided a brief training document discussing disparate impact in the medical redlining context.³²⁰ This document is a step in the right direction in that it addresses a specific context and provides examples. However, it too is unclear on the legal underpinnings

of the standards it references. Although an understanding of the concept of “health care” or “medical necessity” is crucial to a defense raised by a recipient in a disparate case, OCR’s treatment of this important compliance standard simply has not been thoroughly clarified for investigative staff and other key stakeholders, such as recipients and beneficiaries, in recent policy guidance disseminated across all the regions.

For example, OCR does not have recent policy guidance thoroughly clarifying the meaning of the term “health care necessity” as it may be used in cases involving any number of issues that can arise, including discrimination in hospital relocations, the managed care industry, medicaid/medicare programs, cases involving racial medical redlining, “dumping,” or patients with limited English proficiency. A guidance document is needed to explain in simple, direct language, both the legal and practical aspects of the term “health care necessity,” in as many contexts as possible.

Regional attorneys agree that new policy and/or investigative guidance addressing disparate impact standards would be extremely helpful in making OCR enforcement activities more effective as a means of ensuring civil rights compliance.³²¹ For example, one regional attorney has stated that he believes investigative staff in his region do not have sufficient policy guidance on disparate impact standards; and some investigators lack an overall clear understanding of these standards.³²² Another attorney has stated that where there is a disproportionate impact on minorities there is a potential title VI violation and “if OCR put out more policy guidance in the title VI impact area this could be addressed.”³²³ She also stated that a number of regional offices, including her own, thought that because the regulations on disparate impact are “pretty bare boned” even though impact cases represent a continually developing area in civil rights, that further policy guidance on disparate impact cases would be very helpful.³²⁴ Yet another attorney stated that his region recently has begun

³¹⁷ 42 U.S.C. 2000e-2(k) (1994).

³¹⁸ See *New York Urban League, Inc. v. New York*, 71 F.3d 1031, 1036 (2d Cir. 1995) (“[c]ourts considering claims under analogous title VI regulations have looked to title VII disparate impact cases for guidance”).

³¹⁹ PSPS interview, p. 11 (statement of O’Brien).

³²⁰ See HHS, OCR, “Title VI and Disproportionate Impact: Restricted Service Area (Redlining),” revised Dec. 7, 1998, accessed at <<http://www.hhs.gov:343/ocrsec/redline.htm>> (hereafter cited as OCR, “Restricted Service Area”).

³²¹ Freeman interview, p. 3; Miyasato interview, p. 5; Morales interview, p. 15.

³²² Freeman interview, p. 3.

³²³ Miyasato interview, p. 5.

³²⁴ *Ibid.*, p. 4.

to address racial disparity issues. “In thinking for the future, as I come to deal with [these] issues more and title VI, I would welcome guidance on the way disparate impact has been analyzed under title VI,” he said.³²⁵

One regional attorney has suggested that a useful means of disseminating the agency’s position on specific issues or a standard the agency follows in analyzing specific facts is to issue well-written, well-developed letters of finding instead of traditional policy guidance.³²⁶ This would serve the twin purposes of providing a specific example of a how a standard should be applied and taking an abstract principle and turning it into a practical, “real-world” case illustrating the violation of a nondiscrimination provision in a civil rights statute.

For example, OCR’s Region I developed a compliance agreement several years ago in which it clearly and succinctly set forth the salient aspects of OCR’s standard for assessing a recipient’s defense in a disparate impact case.³²⁷ The statement of findings in the resolution agreement states that based on its investigation in the case, OCR has determined that the recipient’s policy “was *not* an action necessary” to achieve its “legitimate, non-discriminatory objective,” which in this case was the physical safety of its employees.³²⁸ OCR stated that to show the necessity of the policy, the recipient would need to show that there were no “available, alternative means of reducing such risks where and when they arise.”³²⁹ OCR determined that “an obvious and available alternative” to the recipient’s policy was to make individualized determi-

nations when safety issues arise.³³⁰ Although a further clarification requiring a heightened standard of justification is needed, this is nonetheless a good example of how OCR applies compliance standards in the disparate impact context and should be disseminated widely.

The term “necessity” is one that can be interpreted very broadly. However, this term may take on new meaning and clarity when viewed in the context of standards set forth by the Supreme Court in conducting discrimination analysis under the equal protection clause of the 14th amendment. For example, in *Washington v. Davis*,³³¹ the Supreme Court stated that racial classifications under the equal protection clause must receive the “strictest scrutiny” by the reviewing court and are justifiable “only by the weightiest of considerations.”³³² More recently, in *Adarand Constructors, Inc. v. Peña*,³³³ the Court held that the Constitution requires “strict scrutiny” analysis, referring to a standard under which the challenged State action must be justified as *narrowly tailored* to further a *compelling state interest*.³³⁴ The dichotomy between strict scrutiny and lesser standards applied to classifications other than race that lies at the heart of the Court’s equal protection analysis closely resembles that between “necessity” and the lesser standard of legitimate justification that courts have considered in disparate impact cases in the health care context.

Analogizing to the equal protection standard, for a challenged health care policy to be legally justified, the health care funding recipient would need to show that the policy served a compelling purpose and that the policy was so narrowly tailored to that purpose that there were no other, less discriminatory means of achieving the objective. The importance of the equal protection analogy for OCR in providing updated guidance to recipients and investigative staff on disparate impact discrimination under title VI is that it shows, in stark terms, the need for recipients to prove a *relationship* between the challenged policy and the objective, such that no other less

³²⁵ Morales interview, p. 15.

³²⁶ Graham interview, p. 10 (stating “One of the things you could do is publicize findings and settlements with greater frequency; then, theoretically, you wouldn’t have to do as much abstract policy if you were using the actual cases as the vehicle for publishing outcomes.”).

³²⁷ Caroline Chang, regional manager, Region I, OCR, HHS, letter to Stephen Savitsky, chairman and chief executive officer, Staff Builders Services, Inc., Lake Success, NY, and Joyce Thomas, commissioner, State of Connecticut, Department of Social Services, Hartford, CT, May 19, 1995 (re: complaint no. 01-94-3050), and attached resolution agreement between HHS, OCR, Region I, and Staff Builders Services, Inc. (hereafter cited as Chang letter, May 19, 1995, and Resolution Agreement re: 01-94-3050, respectively).

³²⁸ Resolution Agreement re: 01-94-3050, p. 8.

³²⁹ *Ibid.*

³³⁰ *Ibid.*, p. 9.

³³¹ 426 U.S. 229 (1976).

³³² 426 U.S. at 2429.

³³³ 515 U.S. 200 (1995).

³³⁴ 515 U.S. at 235 (citing *Fullilove v. Klutznick*, 448 U.S. 448, 496 (1980) (concurring opinion of)).

discriminatory policy could be implemented to accomplish a particular objective. Further, under an equal protection analysis, the objective itself must be compelling, not merely legitimate.

In *Washington*, the Court ruled that the Constitution does not prohibit policies or practices with a disproportionate adverse racial impact so long as such policies are neutral on their face and may be rationally shown to serve a purpose that the government is constitutionally empowered to pursue.³³⁵ However, the HHS title VI regulations specifically prohibiting facially neutral policies that impact disproportionately on racial and ethnic minorities³³⁶ reach beyond the equal protection standard applied to disparate impact discrimination by the Supreme Court in *Washington v. Davis*. Under the title VI regulations such adverse impact is expressly prohibited.³³⁷ The title VI regulations state:

In determining the site or location of a facility, an applicant or recipient may not make selections with the effect of excluding individuals from, denying the benefits of, or subjecting them to discrimination under any program to which this regulation applies, on the ground of race, color, or national origin; or with the purpose or effect of defeating or substantially impairing the accomplishment of the objectives of the Act or this regulation.³³⁸

Given the clear and unequivocal nature of this express prohibition, it seems appropriate for OCR to issue updated policy (and investigative) guidance implementing a more stringent standard for assessing the legitimacy of defendant/recipients' claims than the one applied by most courts that have addressed disparate impact claims in the health care context.³³⁹ OCR can clarify its own position by developing a policy guidance reiterating that its standard for assessing the legitimacy of defendants' claims is a far more rigorous one than that applied in leading decisions such as *Bryan v. Koch*. Further, it should define "necessity" more narrowly, such that the disputed health care policy must,

at a minimum, *significantly* further an *important* legitimate program objective; and that there are no acceptable alternative policies or practices that would better accomplish the health care purpose advanced, or accomplish it equally well with a lesser differential racial impact.³⁴⁰ From a practical standpoint, one commentator noted:

Title VI disproportionate adverse impact claims require not just any legitimate objective but one that is important to the operation of the program. Maintaining a high quality medical program, patient and staff safety, and financial necessity should all qualify as important objectives in the health care context. On the other hand, a mere interest in cutting costs or saving money is not a sufficiently important concern, without some element of financial necessity, to qualify as an important interest.

A federally funded health care defendant should do more than merely assert that the policy furthers an important purpose; it should introduce some empirical evidence establishing the challenged practice is, in fact, effective in furthering an important program need. The greater the disproportionate adverse impact the more effective the challenged practice needs to be to justify its continued use. For example, if a policy excluded almost all minority patients while only incrementally improving the quality of patient care, the policy would not "significantly" further the important, legitimate objective of non-discriminatory, high-quality care.³⁴¹

The commentator points out that the crux of a title VI standard must be to find less discriminatory alternatives for health care policies or practices creating disparate impact, rather than focusing on the strength of the relationship between the policy employed and the goal sought. In this light, the existence of alternatives "serves as proof that the challenged policy is insufficiently related to the hospital's asserted goal or that the hospital's interests advanced by a particular policy are not important enough to justify

³⁴⁰ *Ibid.*, p. 975.

³⁴¹ *Ibid.*, p. 976. See also Golightly-Howell interview, p. 5. This attorney said a defendant would have to go beyond the fact that it was trying to save money when it implemented a certain policy that resulted in a disparity. She stated that the respondent would have to demonstrate that this was an action that was necessary—that there was not another means of reaching the same result that would affect minorities less. OCR would want to see the budget that was in question and some explanations of why the respondent decided to cut in that particular area as opposed to some other areas. *Ibid.*

³³⁵ 426 U.S. at 246–47.

³³⁶ 45 C.F.R. § 80.3(b)(2)–(3) (1998).

³³⁷ For example, section 80.3(b) anticipates specific contexts in which discriminatory practices could arise and explicitly prohibits such practices. *Id.*, § 80.3(b).

³³⁸ *Id.*

³³⁹ See Watson, "Reinvigorating Title VI," pp. 975–77.

use of the policy in light of its disparate racial impact.”³⁴²

None of OCR’s existing guidance to investigative staff is presented with the level of clarity and emphasis on vigorous title VI enforcement advocated in the above commentary, and OCR has not provided recent policy guidance thoroughly addressing any of these critical aspects of title VI enforcement in the disparate impact context.

Developing Model Methods of Administration

The title VI regulations require all State recipients of Federal funds to develop “methods of administration.”³⁴³ These are plans or outlines describing specific activities that a recipient will undertake to ensure compliance with title VI and prevent future civil rights violations. The regulations require that methods of administration “give reasonable assurance that the applicant and all recipients of Federal financial assistance under such program will comply with all requirements imposed by or pursuant to this regulation.”³⁴⁴

OCR has not included in regulations or policy recommendations clear and specific guidance for what to include among methods of administration, although recipients are required to develop them. OCR issued several policy memoranda in the 1970s clarifying requirements for methods of administration.³⁴⁵ OCR may be able to serve its

recipients better by issuing a new policy guidance containing specific recommendations for State recipients to follow in developing their methods of administration. Perhaps this would help to avoid defective methods of administration from being developed by recipients operating without clear guidance.

Title VI Compliance in Specific Contexts

To enforce the civil rights provisions for which it has responsibility, a Federal civil rights agency such as OCR must go beyond developing and disseminating general policy guidance, such as clarifying compliance standards in proving cases of discrimination and establishing model methods of administration. Such an agency also must identify and confront new or resurgent problem areas it has not addressed sufficiently. For example, OCR must act decisively to provide needed guidance when social, economic, and structural developments in the health care industry, such as the managed care revolution, create new potential for discrimination to occur. Guidance is needed in such areas as discrimination in the managed care industry, redlining, selective marketing, or “cherry-picking,” race discrimination in employment and staff privileges, and barriers to adequate health care associated with limited English proficiency.³⁴⁶ For many specific contexts, OCR can benefit its staff, recipients, and beneficiaries of federally assisted programs by developing clear, detailed, comprehensive policy describing the forms discrimination can take and the efforts recipients can take to ensure that it does not occur. Some of these contexts are discussed below.

Managed Care

“The United States has a long-standing history of discrimination in health care, and a large body of evidence on access and quality suggests ongoing problems faced by minority Americans. This history and evidence underscore the impor-

³⁴² Watson, “Reinvigorating Title VI,” p. 976.

³⁴³ 45 C.F.R. § 80.4(b)(2) (1998).

³⁴⁴ *Id.*

³⁴⁵ See Louis H. Rives, Jr., director, Health and Social Services Division, OCR, U.S. Department of Health, Education, and Welfare, memorandum to Eileen P. Bradley, Administration on Aging, Social and Rehabilitation Services, U.S. Department of Health, Education, and Welfare, Feb. 28, 1973 (re: applicability of existing methods of administration to State plans covering the nutrition program for the elderly) (hereafter cited as Rives memo); Edward H. Redman, chief, Race Discrimination Branch, OCR, U.S. Department of Health, Education, and Welfare, memorandum to Burton M. Taylor, director, Division of Standards and Policy Development, OCR, U.S. Department of Health, Education, and Welfare, Nov. 16, 1979 (re: Hawaii State Health Planning and Development Agency, LOF, case #09-79-7003) (hereafter cited as Redman memo); Burton M. Taylor, director, Division of Standards and Policy Development, OCR, U.S. Department of Health, Education, and Welfare, memorandum to Floyd Pierce, regional director, Region IX, OCR, U.S. Department of Health, Education, and Welfare, Dec. 13, 1979 (re: Arizona Department of Health Services, LOF,

case #09-79-7005) (hereafter cited as Taylor memo); Chavkin letter.

³⁴⁶ Many of these specific contexts are applicable to both title VI and the Hill-Burton nondiscrimination provisions, if a facility received funds under the Hill-Burton Act. Issues affecting women may fall under title IX, if the facility receiving HHS funds is part of an educational institution. However the main emphasis of this discussion is on title VI because its impact is the broadest.

tance of developing a new framework for measuring and ensuring equal access in a managed care context."³⁴⁷

"The greater potential for managed care to produce an adverse impact in the case of minority Americans results from the fact that managed care arrangements have been superimposed on an underlying health care system with a history of discrimination."³⁴⁸

The potential for discrimination, particularly racial/ethnic discrimination, in the context of managed care is significant and is recognized by OCR and leading commentators and advocates for civil rights in health care delivery, services, or treatment.³⁴⁹ Several managed care practices can have a disparate effect on minorities. These practices provide examples of the inseparability of economics and race in decisions of managed care organizations. For example, one of the ways in which managed care organizations (MCOs) can discriminate against minorities is in their selection of providers.³⁵⁰ A physician or other type of provider who serves mainly poor minorities may not be included in a managed care network because the provider's patients might be labeled "too costly."³⁵¹ Similarly, managed care organizations often discourage enrollment of poor and minority patients because they are perceived as costly patients.³⁵² Further, some plans essentially enroll patients from suburban areas only by sending brochures to the suburban

neighborhoods, while ignoring inner-city areas, a process known as selective marketing, or "cherry picking."³⁵³ In addition, while managed care plans do not have official policies of denying poor and minority patients medications, procedures, or tests given to more affluent whites, according to at least one commentator the cost-saving structure of managed care promotes differential treatment.³⁵⁴

Medicaid managed care shares the fundamental characteristics of private managed care, but has unique qualities of its own that affect poor women and minorities. In addition to keeping medical costs low, the purpose of the Medicaid managed care system is to increase health care access for the poor.³⁵⁵ While the managed care system has the potential to accomplish this, there are also potential adverse effects on the Medicaid population and the uninsured, who are predominately women and minorities, including reduced access for the uninsured; decreased services to Medicaid patients; inappropriate definitions, measures, policies, and procedures; and continued discrimination.³⁵⁶ According to one commentator, Medicaid man-

³⁴⁷ Sara Rosenbaum and Peter Shin, "Medicaid Managed Care: Opportunities and Challenges for Minority Americans," October 1998, prepared for the Joint Center for Political and Economic Studies under a grant from the Henry J. Kaiser Family Foundation, p. 23.

³⁴⁸ Rosenbaum and Shin, "Medicaid Managed Care," p. 24.

³⁴⁹ See chaps. 2-3. See also Sara Rosenbaum and Peter Shin, "Medicaid Managed Care," p. 28.

³⁵⁰ See, e.g., David Nerenz, "Medicaid Managed Care and Minority Populations: Issues in Quality of Care," Joint Center for Political and Economic Studies, September 1998, pp. 3-4; see also Rosenbaum and Shin, "Medicaid Managed Care," p. 28 (citing Editor's note, "The Impact of Managed Care on Doctors Who Serve Poor and Minority Patients," *Harvard Law Review*, vol. 108 (May 1995), p. 1625) (hereafter cited as Editor, *Harvard Law Review*, "Impact of Managed Care").

³⁵¹ See Nerenz, "Medicaid Managed Care and Minority Populations," pp. 3-4.

³⁵² See *ibid.*, p. 319; see also Rosenbaum and Shin, "Medicaid Managed Care," p. 27.

³⁵³ David Barton Smith, *Health Care Divided: Race and Healing a Nation* (Ann Arbor, MI: University of Michigan Press, 1999), p. 317; Marianne Engelman Lado, assistant professor, School of Public Affairs, Barruch's College, New York, NY, telephone interview, Jan. 11, 1999 (hereafter cited as Lado interview). See also Rosenbaum and Shin, "Medicaid Managed Care," p. 28.

³⁵⁴ See generally Vernellia R. Randall, "Impact of Managed Care Organizations on Ethnic Americans and Underserved Populations," *Journal of Health Care for the Poor and Underserved*, vol. 5, no. 3 (1994). Other forms of discrimination by MCOs are designed to make facilities less accessible such as location or relocation of services, ambulance patterns that divert publicly insured patients away from certain facilities and policies that require appointments to be made by telephone (reducing access among patients without telephones); segregated patient wards; service reductions that fall with unequal weight on minority groups; and specialty practice guidelines that, while ostensibly neutral, disproportionately curtail care to minority patients. See Sara Rosenbaum, Rafael Serrano, Michele Magar, and Gillian Stern, "Civil Rights in a Changing Health Care System," *Health Affairs*, vol. 16, no. 1 (January/February 1997), p. 97 (hereafter, Rosenbaum et al., "Civil Rights in a Changing Health Care System").

³⁵⁵ Darrell J. Gaskin, "Access to Health Care in a Managed Care Environment," executive summary, Joint Center for Political and Economic Studies, May 1998, p. 2; see also Rosenbaum and Shin, "Medicaid Managed Care," p. 9.

³⁵⁶ See Rosenbaum and Shinn, "Medicaid Managed Care," p. iv.

aged care may put the health care safety net at risk because facilities that normally serve the uninsured may have less Medicare and Medicaid income, as these patients opt to be treated by providers affiliated with for-profit facilities.³⁵⁷ Further, capitation payments that reimburse less than the costs of care may cause health plans to withhold certain services from Medicaid beneficiaries.³⁵⁸

Forms of Discrimination

Despite indications of discrimination prohibited under title VI, OCR has not yet developed policy guidance specifically addressing title VI compliance in the managed care context. OCR regional staff and civil rights attorneys who have litigated health care related cases have recommended strongly the need for OCR to develop policy guidance on managed care issues. For example, one regional manager said that a recent OCR investigation into Medicaid managed care indicated the need for policy guidance for managed care organizations.³⁵⁹ His staff investigated the lack of services for beneficiaries with limited English proficiency by a Medicaid managed care provider in Pennsylvania. According to the regional manager, the managed care organization did not know what OCR was nor did it understand its title VI responsibilities.³⁶⁰ As a result, his staff had to meet with representatives of the managed care organization to provide technical assistance and training on civil rights issues. A compliance review of a Maryland managed care organization yielded the same results: the managed care organization did not know what OCR was and what its civil rights responsibilities were.³⁶¹

Another OCR regional manager stated that OCR is just beginning to learn about the differ-

ent civil rights issues associated with managed care organizations, such as marketing to minorities and redlining. He noted that because managed care is evolving so fast, OCR must stay ahead of the curve to understand all of the issues, but it lacks the requisite resources to do so.³⁶² These regional managers believe that policy guidance would benefit both MCOs and investigative staff. Moreover a civil rights litigator and scholarly commentator who is an expert on civil rights issues in health care has stated that she thinks both OCR staff and managed care organizations need some form of guidance on managed care issues.³⁶³

Policy on managed care is needed to help investigative staff to more effectively conduct compliance reviews in the managed care setting. Moreover, any policy guidance on managed care must contain a detailed discussion providing fact-based and or hypothetical examples of the many forms of illegal and potentially illegal discrimination occurring in the context of Medicaid and describing nondiscriminatory alternative practices. For example, there is evidence that the following forms of discrimination may be affecting Medicaid beneficiaries:

- *Segregated Provider Lists.* A managed care organization may develop two separate provider networks, one of providers who accept Medicaid patients and one of only providers who do not accept Medicaid.³⁶⁴ A recent study by the New York City Office of the Public Advocate,³⁶⁵ according to commentators, “uncovered widespread evidence of segregated networks of providers within health plans serving areas in which both Medicaid and privately sponsored enrollees reside. . . . In other words, within a single service area, plans appear[ed] to be giving Medicaid enrollees access to only a portion of their provider networks, even though the Medicaid

³⁵⁷ Rosenbaum and Shinn, “Medicaid Managed Care,” p. iv. Fortunately, the reduction in access resulting from this dynamic has not been pronounced. Thus far there is no evidence that safety-net providers have reduced their care of uninsured patients. *Ibid.*, p. 4.

³⁵⁸ Capitation payments are fixed amounts paid to providers based upon the number of patients. See Nerenz, “Medicaid Managed Care and Minority Populations,” p. 3.

³⁵⁹ Paul Cushing, regional manager, Region III, OCR, HHS, telephone interview, Feb. 23, 1999, pp. 6–7 (hereafter cited as Cushing interview).

³⁶⁰ *Ibid.*

³⁶¹ *Ibid.*

³⁶² Pollack interview, p. 8.

³⁶³ Lado interview, p. 22.

³⁶⁴ Rosenbaum and Shin, “Medicaid Managed Care,” p. 28; Lado interview.

³⁶⁵ Rosenbaum et al., “Civil Rights in a Changing Health Care System,” p. 99.

patients [were] demonstrably underserved."³⁶⁶

- *Service Area and Enrollment.* These commentators also have reported on evidence of managed care organizations that seek contracts limited to certain service areas, including plans that seemingly try to avoid service areas in inner-city areas with high concentrations of minority beneficiaries in favor of more suburban area plans with lower proportions of minority residents.³⁶⁷
- *More restrictive definition of "medical necessity."* As cost-saving measures, MCOs might apply a narrower definition of "medical necessity" to their medicaid patients, using the rationale that these patients are more expensive to treat. Since medicaid patients are disproportionately minority, this practice is a potential title VI violation.³⁶⁸
- *Longer waiting times for new patient or urgent care appointments.* Also in an effort to save costs, MCOs might delay appointments for new or emergency medicaid patients. This practice has been encountered by pregnant women on medicaid trying to obtain prenatal care.³⁶⁹

These and other forms of discrimination illustrate that OCR policy guidance, particularly guidance targeted toward investigative staff, must address systemic disparate impact in the health care industry. Recently, commentators have observed:

[E]ffective civil rights advocacy must be able to identify industry activities that might in fact be the cause of statistically disparate treatment. This in turn depends on having a high level of understanding of how the enterprise in question operates. Because the health care industry is so vast and complex, the number of civil rights challenges to its conduct have been few in relation to civil rights efforts in other human

³⁶⁶ Ibid. (citing Office of the Public Advocate of New York, *Two Lists: Commercial and Medicaid Managed Care Providers* (1995)).

³⁶⁷ Ibid., p. 98. This practice is known as "redlining" and is discussed in more detail in the discussion below.

³⁶⁸ Rosenbaum and Shin, "Medicaid Managed Care," p. 28.

³⁶⁹ Ibid. See also Gordon Bonnyman, managing attorney, Tennessee Justice Center, Nashville, TN, telephone interview, Feb. 14, 1999 (hereafter cited as Bonnyman interview). Mr. Bonnyman designed tests to detect discrimination against medicaid mothers-to-be.

service areas with similar histories of *de jure* segregation, such as education.³⁷⁰

OCR's Efforts to Address Discrimination in Managed Care

Discrimination against medicaid patients violates not only title VI and title IX, but also Hill-Burton, which has explicit prohibitions against discrimination.³⁷¹ Titles VI and IX prohibit policies or procedures that disproportionately disadvantage minorities and women. Since medicaid beneficiaries are disproportionately women and minorities, a policy or procedure that adversely affects medicaid beneficiaries can be a violation of titles VI and perhaps IX.

Aside from hosting a 1995 training session about the potentially discriminatory activities of managed care organizations,³⁷² OCR has done little to encourage and support the regional investigators in identifying cases of discrimination. OCR needs to publish some form of guidance to better educate the public, recipients, and regional investigators about racial/ethnic discrimination, both disparate treatment and disparate impact, in the managed care setting. This guidance may take the form of guidelines, or at the least a policy guidance memorandum, published in the *Federal Register*. The guidance should communicate explicitly that selective marketing, redlining, segregated provider lists, and decreased services for medicaid beneficiaries are violations of title VI and Hill-Burton. It should describe these activities using concrete examples so that the composition of the unlawful behavior is clearly observable. This would not only provide guidance for investigators, but also would afford a measure of deterrence to MCOs, as well as a warning for the public to beware of racial/ethnic discrimination by MCOs.

In the midst of the health care industry's dramatic transformation to a managed care system, OCR has done little beyond taking notice. OCR has established managed care as a priority

³⁷⁰ Rosenbaum et al., "Civil Rights in a Changing Health Care System," p. 94.

³⁷¹ The community assurance provision of the HHS regulation implementing Hill-Burton states that a facility that has received Hill-Burton funds shall make the services it provides available without discrimination on the basis of race, color, national origin, creed, or any other ground unrelated to the individual's need for the service or the availability of the needed service in the facility. 42 C.F.R. § 124.603(a)(1) (1998).

³⁷² See chap. 2.

issue in its 1994 strategic plan and 1996–1998 annual implementation plans. Nonetheless, OCR thus far has failed to provide the kind of in-depth, fully developed guidance needed on title VI and Hill-Burton discrimination in the context of managed care. The agency has not promulgated any guidelines or given its regional offices adequate policy guidance on how to identify and eliminate race or gender discrimination by MCOs. Such guidance, if developed properly, can accomplish two important goals. First, it can inform recipient MCOs of how to keep from violating title VI, title IX, and Hill-Burton. Second, it can provide investigative guidance on uncovering MCO violations to be used by the OCR regional offices. In fact, several of the regional employees interviewed stated that they would benefit from policy guidance and training by OCR on race discrimination by managed care organizations.³⁷³

The lack of attention to this issue probably has more to do with a dearth of focused leadership within OCR. Perhaps there has been a lack of complaints because patients are not informed on the subject. They may not be aware of the discrimination they are experiencing, that there is a Federal agency empowered to ensure their rights in this regard, or they simply may not know how to seek redress for the discrimination they are experiencing. Also, OCR's failure to schedule compliance reviews could be based on the fact that the personnel at OCR's regional offices are not equipped to investigate managed

care organizations for race or gender discrimination.³⁷⁴

Developing Policy Guidance

For OCR to provide the kind of comprehensive guidance document to recipients and its own staff that is needed to address discrimination in managed care, it must first develop a basic background section for such a document. In this section, an overview of the managed care phenomenon would be helpful to provide a broad-based perspective. For example, this discussion might make observations about the trend toward managed care, particularly its emphasis on cost containment.

The heart of a policy guidance on managed care must be the potential for discrimination under title VI within the system. Such a guidance would note that, while the advent of managed care has resulted in cost savings, it has not been a panacea for health care access and quality issues. Not only has it failed to erase some of the inequities inherent in the traditional health care system, it has also brought with it new challenges, including reduced freedom of choice, reduced access to certain services, questions about quality assurance, and continued discrimination. As one group of commentators has written:

The evolution of the health care system from fee-for-service to managed care holds much promise for minority persons, who historically have faced serious, extensively documented barriers to health care access. However, managed care providers, like their fee-for-service counterparts, may perpetuate past discriminatory practices in new ways. Understanding forms of discrimination is important at this stage of the development of managed care, when program design and policy action can most effectively prevent the occurrence of such practices.³⁷⁵

Limited English Proficiency

“Language barriers foster powerlessness by limiting the choices of [language minorities] and their ability to acquire knowledge that will enable them to make decisions to access or use health

³⁷³ Cushing interview, p. 7 (stating that his staff have not received training on managed care issues in 4 years despite a consensus that more training was needed); Miyasato interview, p. 4 (stating that Region X investigators do not feel they have all of the tools or guidance needed to conduct effective enforcement activities in the managed care context); Graham interview, p. 3 (observing that there is no good investigative plan to use in searching for discrepancies in health status in the area of managed care); George Bennett, Sandra Brumly, and Delores Wilson, equal opportunity specialists, Region VI, OCR, HHS, telephone interview, Feb. 2, 1999, p. 18 (stating “I also go back to better training and additional training on the health care issues as [they] relate to title VI. Case law training would be helpful, and as managed care evolves, we could use training to develop strategies because managed care is a different animal”) (statement of Bennett).

³⁷⁴ There are several compliance reviews of managed care organizations, but these are looking for discrimination on the basis of disabilities.

³⁷⁵ Rosenbaum et al., “Civil Rights in a Changing Health Care System,” p. 91.

care. Language barriers limit [minorities'] opportunities for obtaining needed information . . . and keep them from understanding the risks of health-related decisions."³⁷⁶

One context that OCR has begun to address in policy, although not regulatory guidance, is limited English proficiency (LEP). For example, OCR recently has issued a guidance memorandum on LEP issues intended for investigative staff that also was disseminated widely outside the agency.³⁷⁷ This guidance memorandum, transmitted to staff by OCR's deputy director on February 5, 1998, addresses title VI compliance in health care service delivery in the context of national origin discrimination against persons with limited English proficiency.³⁷⁸

Overall, the LEP guidance is a thorough, detailed document. OCR worked closely with the Department of Justice Coordination and Review Section (CORS) staff to develop it and it has earned the praise of CORS for its effectiveness as an investigative guidance.³⁷⁹ It discusses relevant case law, regulations, and guidelines. In addition, the guidance includes detailed analyses of certain issues and provides helpful examples. However, the guidance does not adequately address such issues as the diversity of languages spoken in many regions of the country and the need for highly trained interpreters.³⁸⁰ Nonetheless, with some additional information included, this document may be used as a model format for developing more guidance on substantive issues relating to title VI enforcement in

specific contexts that the agency has yet to address.

Discussion of Relevant Case Law

The first important aspect of the LEP guidance, its discussion of relevant case law and regulatory provisions, represents a notable difference between this guidance and some earlier OCR guidance from the 1980s. The guidance expressly states that it is "intended to clarify standards consistent with case law and well established legal principles that have been developed under title VI."³⁸¹ This inclusion of the legal underpinnings of discrimination against persons with limited English proficiency makes the guidance better suited to assist investigative staff in developing a full understanding of the standards they are relying on to make determinations as to the presence of discrimination in cases involving limited English proficiency. The guidance is an improvement over earlier efforts, particularly with respect to the level of detail and legal and practical analysis it contains.

For example, the guidance discusses the *Lau v. Nichols* case, a seminal Supreme Court decision addressing title VI implementation and enforcement in the context of limited-English-proficient individuals.³⁸² Although this case related to public education and not health care delivery, the guidance recognizes that the case should have significant implications for HHS' enforcement of title VI. In particular, as the guidance notes, recipients of Federal funding are prohibited under title VI and *Lau* from:

adopting and implementing policies and procedures that exclude or have the effect of excluding or limiting the participation of beneficiaries in their programs, benefits or activities on the basis of race, color, or national origin. Accordingly, a recipient must ensure that its policies do not have the effect of excluding from, or limiting the participation of, such persons in its programs and activities, on the basis of national origin. Such a recipient should take reasonable steps to provide services and information in appropriate languages other than English in order to ensure that

³⁷⁶ Teresa C. Juarbe, "Access to Health Care for Hispanic Women: A Primary Health Care Perspective," *Nursing Outlook*, vol. 43 (January/February 1995), p. 26.

³⁷⁷ PSPS interview, p. 8 (statement of Kathleen O'Brien); Kathleen O'Brien, special assistant to the acting director for Civil Rights; Patricia Mackey, deputy to the associate director, Office of Program Operations, OCR; Valita Shepperd, deputy director, Program Development and Training Division, Office of Program Operations; Ronald Copeland, associate deputy director, Office of Program Operations; Johnny Nelson, deputy director of Voluntary Compliance and Outreach Division, Office of Program Operations; Toni Baker, director of Investigations Division, Office of Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13 and 18, 1998, pp. 24, 43-44 (statements of Patricia Mackey) (hereafter cited as OPO interview).

³⁷⁸ See generally OCR, "Guidance Memorandum on Limited English Proficiency."

³⁷⁹ CORS interview, p. 4.

³⁸⁰ See discussion below.

³⁸¹ OCR, "Guidance Memorandum on Limited English Proficiency," p. 1.

³⁸² 414 U.S. 563 (1974).

LEP persons are effectively informed and can effectively participate in and benefit from its programs.³⁸³

This statement emphasizes for investigative staff, as well as recipients and beneficiaries of Federal funding, the statutory basis for investigating how well recipients are addressing barriers to health care access for persons with LEP. However, the language stating that recipients should take "reasonable steps" to ensure that LEP persons are "effectively informed and can effectively participate in and benefit from its programs" is not entirely clear. For example, the term "reasonable" obviously is somewhat ambiguous and begs the question of what actions by recipients would constitute "reasonable steps." Unfortunately the guidance does not contain a section providing more clarity with respect to these terms. While it is intuitive that what is "reasonable" will vary from recipient to recipient, the guidance would be stronger with a section that expressly stated this and provided a discussion on standards that should be applied in making this determination.

Specific Issues Relating to Limited English Proficiency

Another noteworthy aspect of this guidance memorandum is that it provides careful analysis of specific issues relating to patients with limited English proficiency. The guidance includes introductory observations that illustrate the importance of providing specific guidance to OCR staff and recipients on title VI compliance requirements relating to limited English proficiency. For example, the memorandum states:

English is the predominant language of the United States and according to the 1990 Census is spoken by 95% of its residents. . . The United States is also, however, home to millions of national origin minority individuals who are limited in their ability to speak, read, write and understand the English language. The language barriers experienced by these LEP persons can result in limiting their access to critical public health, hospital and other medical and social services to which they are legally entitled and can limit their ability to receive notice of or understand what services are available to them. . . .

LEP persons can and often do encounter barriers to health care and social services at nearly every level

³⁸³ OCR, "Guidance Memorandum on Limited English Proficiency," pp. 1-2.

within such programs. . . . Many health and social services programs provide information about their services in English only. Many LEP persons presenting at hospitals or medical clinics are faced with receptionists, nurses and doctors who speak English only, and often interviews to determine eligibility for medical care or social services are conducted by intake workers who speak English only.³⁸⁴

By opening its discussion with specific examples of potential discrimination, the guidance provides investigative staff with a better understanding of how barriers faced by persons with limited English proficiency can result in title VI compliance problems. The guidance includes other specific examples of potential compliance problems among recipients, and addresses several key topics, such as who is covered, ensuring equal access to LEP persons, interpreter services, and compliance and enforcement.

In the section on ensuring LEP persons equal access, the guidance is effective in that it provides precise meanings for the standards it identifies. For example, the guidance states that "[t]he key to ensuring equal access to benefits and services for LEP persons is to ensure the service provider and the LEP client can communicate effectively."³⁸⁵ It states explicitly that effective communication means "the LEP client should be given information about, and be able to understand, the services that can be provided by the recipient to address his/her situation and must be able to communicate his/her situation to the recipient service provider."³⁸⁶ The memorandum provides several examples of the measures a recipient must take to ensure effective communication, including procedures for identifying the language needs of patients/clients, access to proficient interpreters in a timely manner during hours of operation, written policies and procedures on interpreter services, and the dissemination of interpreter policies and procedures to staff.³⁸⁷

The section on interpreter services provides many examples of measures that would help ensure compliance by recipients. These include hiring bilingual staff and staff interpreters, using volunteer staff interpreters, and developing

³⁸⁴ *Ibid.*, p. 2.

³⁸⁵ *Ibid.*, p. 4.

³⁸⁶ *Ibid.*, pp. 4-5.

³⁸⁷ *Ibid.*, p. 5.

a notification and outreach plan for LEP beneficiaries.³⁸⁸ This section also expressly names practices that may result in a finding of non-compliance with title VI. For example, the guidance states that a recipient should not require beneficiaries to use friends or family members as interpreters.³⁸⁹ This recommendation relates to a significant problem faced by persons with limited English proficiency, particularly women. For example, according to staff of the New York Task Force on Immigrant Health:

All too often, a family member, who may be a child, is relied on to interpret. S/he may feel that s/he must protect the patient and delete "bad news." Family members may also have their own agendas. For example, husbands who batter their wives may censor any information concerning an abusive situation when interpreting for them.³⁹⁰

In another example, OCR addressed a case in which hospitals in Greenville, South Carolina, were allowing family members to act as interpreters during the administering of epidurals for women in active labor.³⁹¹ In some instances, OCR found that no interpreter was used at all. One of the more grievous results of this practice was that several women with limited English proficiency failed to receive epidurals because the hospital neglected to make any effort to ensure adequate interpreting services.³⁹² Ultimately, OCR entered into an agreement with the hospital system to clarify its policy on epidurals for non-English-speaking patients in labor and delivery.³⁹³ As these cases illustrate, there can

be potentially serious consequences when family members are used as interpreters. Therefore, it is unfortunate that OCR's guidance does not prohibit recipients from forcing beneficiaries to use family members as interpreters.

The guidance does indicate that a recipient should ensure that the persons it uses to provide interpreter services are competent.³⁹⁴ However, the guidance states that "[c]ompetency does not necessarily mean formal certification as an interpreter."³⁹⁵ It also states that "it would be inappropriate to use a person who had little knowledge of medical terms or a person who spoke English poorly."³⁹⁶ These statements reflect a significant weakness in OCR's policy with respect to persons with LEP. It is extremely important for the individuals serving as interpreters to be highly trained both in language interpreting and medical terminology. According to staff of the New York Task Force on Immigrant Health, among the serious problems that can result from using untrained or minimally trained interpreter services are: miscommunication between provider and patient on extremely important medical questions; violation of doctor-patient confidentiality; treatment of patients prior to informed consent to do so; diagnostic errors; patients' failure to adhere to instructions for medication and other general instructions; missed appointments; and ultimately, negative health outcomes.³⁹⁷

The memorandum, however, sends the message to investigative staff and to recipients that compliance in the LEP context may be fully addressed without any real effort to ensure quality in the interpreting services provided. Without some form of quality assurance measure, such as proof of interpreter certification, OCR cannot ensure that persons with LEP are receiving the equal access to recipients' programs required under title VI. OCR's efforts to ensure that all recipients have the highest quality interpreters may fall outside the scope of this guidance memorandum. However, the statements it contains with regard to interpreter services signify that applying rigorous quality standards for in-

³⁸⁸ Ibid.

³⁸⁹ Ibid., p. 6.

³⁹⁰ Francesca Gany and Heike Theil De Bocanegra, "Overcoming Barriers to Improving the Health of Immigrant Women," *Journal of American Medical Women's Association*, vol. 51, no. 4 (August/October 1996), p. 157.

³⁹¹ Henry F. Barbour, III, acting director, Investigations Division, Region IV, OCR, HHS, letter to Sally McMillan Purnell, attorney at law, Haynesworth, Marion, McKay, & Guerard, L.L.P., Greenville, SC, Feb. 8, 1999 (re: docket no. 04-98-3136), p. 1 (hereafter cited as Barbour letter).

³⁹² Jane Perkins, National Health Law Program, telephone interview, Feb. 5, 1999, pp. 2-3 (hereafter cited as Perkins interview).

³⁹³ Inho Yoon, M.D., memorandum to Obstetrical Resident Staff, et al., Oct. 28, 1998 (re: epidurals for non-English-speaking patients in labor and delivery). The new policy states that an epidural will not be administered to a laboring person until an effective interpreter is available.

³⁹⁴ OCR, "Guidance Memorandum on Limited English Proficiency," p. 6.

³⁹⁵ Ibid.

³⁹⁶ Ibid.

³⁹⁷ Gany and De Bocanegra, "Overcoming Barriers," p. 155.

interpreter services to all recipients presents an objective unrelated to OCR's responsibilities to assess title VI compliance, when in fact, quality assurance measures are an integral part of ensuring equal access and nondiscrimination under title VI.

One OCR regional attorney has noted that the guidance has another significant weakness with respect to interpreter services. He expressed concern that the guidance does not provide a formula for deciding at what point a population in a service area needs to be represented by an interpreter.³⁹⁸ This is obviously an important concern that OCR should address in its policy guidance.

Compliance and Enforcement

The memorandum on compliance and enforcement provides the following guidance to investigative staff:

In determining a recipient's compliance with title VI, OCR's concern will be whether the recipient's system allows LEP beneficiaries to overcome language barriers and thus have equal access to, and an equal opportunity to participate in, health care and social service programs and activities. . . . While a recipient is not required to use the options listed, and may use options that are equally effective, a recipient's appropriate use of the options and methods discussed in this guidance, will be viewed by OCR as evidence of a recipient's intent to comply with its title VI obligations.³⁹⁹

The guidance is not altogether clear in that it refers to a system that "allows LEP beneficiaries to overcome language barriers" and "options that are equally effective," yet the memorandum does not include a wide range of specific examples that would help to clearly define the meaning of this language. Rather, the memorandum provides only two examples to clarify these phrases:

For example, a small health care clinic that accepts patients by appointment only and serves a small but significant LEP population may be able to meet its responsibility to its LEP clients by making arrangements for interpreter services on an as needed basis, and appropriately publicizing the availability of such arrangements.

³⁹⁸ Morales interview, p. 4.

³⁹⁹ OCR, "Guidance Memorandum on Limited English Proficiency," p. 8.

On the other hand, the emergency room in a large hospital located in an area with a larger and more diverse LEP population may require a combination of language assistance options. In this setting there are likely to be a variety of patient contact points, and immediate and accurate information to and from patients is usually critical. In such a situation the recipient also should have staff that are bilingual in English and other frequently encountered languages, in critical patient contact positions.⁴⁰⁰

These two examples provide a kind of "ball park" or "rule of thumb" form of guidance to investigative staff in making determinations as to whether compliance has been achieved. These examples are, to some extent, suggestive of the kinds of program elements OCR investigative staff should be seeking as they conduct their investigations. The guidance, however, does not provide examples of "as needed" services or what might constitute a "small but significant" LEP population. A more exhaustive listing of examples with fact patterns, as well as more specificity on the terms denoting hospital and LEP population size, would have made the memorandum stronger as investigative guidance on title VI compliance in the LEP context.⁴⁰¹

This lack of specificity and illustrative examples has been noted by OCR staff. For example, several regional attorneys have stated that they believe the guidance is inadequate.⁴⁰² One regional attorney criticized the guidance in part because she thinks it uses a standard that is not legally supportable and therefore "raises more questions than it answers."⁴⁰³ The legally insupportable aspect of the guidance derives from the omission of limited English proficiency from the language of the title VI statute and OCR's current title VI regulations. Because the subject matter of the guidance is not codified in a statute or substantive regulation, the guidance does not carry the force of law behind it.⁴⁰⁴ This at-

⁴⁰⁰ Ibid.

⁴⁰¹ One OCR attorney stated that he thinks the current LEP guidance does not provide the kind of concrete formula for determining what solutions need to be applied in particular situations. Morales interview, p. 4.

⁴⁰² See Graham interview, pp. 4, 18; Miyasato interview, p. 3.

⁴⁰³ Miyasato interview, p. 3.

⁴⁰⁴ See Rhinehart interview p. 10; Pollack, interview, p. 4 (noting that the title VI regulations could be improved in the area of LEP. He noted that there has been an ongoing debate over whether LEP should be addressed in the title VI regulations—there currently is nothing in the title VI stat-

torney also thought that the guidance needed less concentration on statutory and regulatory interpretation and more explanation on substantive issues affecting LEP populations, beyond the discussion on interpreter services.⁴⁰⁵

This section of the memorandum does not include a discussion on what means OCR intends to use to ensure that recipients are actually implementing the policies or procedures they agree to in addressing compliance problems found during a complaint investigation or compliance review. This is a matter of particular importance in large part because, as the guidance states, the barriers to access for LEP persons in the health care setting are pervasive and profound. OCR can hardly expect that recipients who agree to implement such policies by having interpreters present in emergency rooms are always going to fully comply. Compliance review followup and monitoring therefore seem especially crucial in LEP-related title VI compliance issues. This memorandum would be more effective as guidance to investigative staff if it included a discussion on specific monitoring objectives and methods with respect to LEP-related compliance issues.

Despite some flaws with respect to the clarity and thoroughness of its presentation and the policy position suggested with regard to requirements for skill levels in interpreting services, this memorandum provides the kind of effective guidance on specific title VI compliance issues that is required to ensure thorough complaint investigations and compliance reviews by OCR.⁴⁰⁶ However, it reflects only a beginning to the development of a policy program that addresses a wide range of title VI compliance issues among health care recipients. Even in the LEP context, OCR could do more to better ensure compliance among funding recipients.

ute that talks about the provision of bilingual services, whether interpreters or bilingual staff were required, what kinds of materials need to be translated, etc.). He stated that it would be useful to have some regulatory standards on LEP. Ibid.

⁴⁰⁵ Miyasato interview, p. 3.

⁴⁰⁶ One regional attorney in Region II stated that he thinks that OCR needs better guidance on LEP/title VI issues and that the current standards are as not as useful for investigators as they could be. He thinks that the guidance on LEP needs no more specific directions on how to handle such cases. Morales interview, p.4.

Need for Formal LEP Regulations

One way in which OCR could improve compliance would be to promulgate formal LEP regulations. The guidance memorandum is an excellent first step, but because OCR did not issue the guidance pursuant to formal rulemaking procedures, it does not carry the force of law.⁴⁰⁷ Formal regulations, published in the *Federal Register* and subjected to a notice and comment period, would legally bind recipients. This would afford OCR more control over recipients' policies and practices on the provision of interpreters.

One OCR regional attorney described a case in which OCR found that a Philadelphia hospital was providing health care services to only 10 percent of the Hispanic population in its service area.⁴⁰⁸ According to this attorney, OCR believed that part of the reason for this was the hospital's failure to conduct outreach and education in the community and to publish its medical informational materials, such as posters and pamphlets, in Spanish as well as English.⁴⁰⁹ OCR entered into negotiations to compel the hospital to conduct outreach and education efforts with the Hispanic community in its service area.⁴¹⁰

However, the hospital's counsel informed OCR that it did not have the legal authority to compel the hospital to conduct these activities because nothing in the title VI statute or OCR's title VI regulations requires nondiscrimination on the basis of limited English proficiency.⁴¹¹ Moreover, the requirement for nondiscrimination on the basis of national origin does not explicitly cover limited English proficiency.⁴¹² Because the only "authority" that OCR has is its guidance memorandum on limited English proficiency, the hospital has a strong argument that it is not required to do anything to remedy the lack of health care service delivery to the Hispanic population in its service area. This example shows how little authority OCR has to compel health care facilities to comply with its guid-

⁴⁰⁷ See Rhinehart interview, p. 10.

⁴⁰⁸ Rhinehart interview, pp. 9-10.

⁴⁰⁹ Ibid.

⁴¹⁰ Ibid.

⁴¹¹ Ibid.

⁴¹² However, this prohibition can be inferred from the general provision of the regulations that prohibits agencies from using criteria or methods of administration that have the effect of subjecting individuals to discrimination because of their race, color, or national origin. See 45 C.F.R. 80.3(b)(2) (1998).

ance. Rather, without regulatory authority, OCR must rely on health care recipients' willingness to participate in the negotiated settlement process.

As noted above, OCR has developed an internal draft regulation addressing title VI discrimination specifically in the context of limited English proficiency. The proposed regulation would have prohibited certain specific practices including subjecting a beneficiary to unreasonable delays in the provision of services because the beneficiary has limited English proficiency and requiring a beneficiary to provide an interpreter or to pay for the services of an interpreter. One commentator praised this draft regulation as "an excellent starting point for a proposed rulemaking by HHS on linguistic accommodation."⁴¹³ This commentator noted that the affirmative obligation on health care facilities would be "based on the number of limited-English-proficient persons sharing the same language in the health care facility's beneficiary population" thus obviating "concerns that, under such a regulation, health care facilities would face excessive burdens by having to anticipate every possible language discordance between a health care consumer and provider."⁴¹⁴

OCR should issue a final rule based in part on this draft regulation.⁴¹⁵ This is particularly important since the guidelines provided in this draft regulation complement the guidance OCR has provided in the LEP memorandum which itself is a notable first step in establishing the program of policy development OCR has been lacking for so many years.

Medical Racial Redlining

Medical racial redlining is an issue of concern to HHS, particularly in OCR Region I.⁴¹⁶ Originally coined in reference to discrimination in the

home mortgage industry, the term has acquired a broadened application, and refers to the practice of excluding certain classes of applicants or potential customers from services based on the perception of high financial risk.⁴¹⁷ In health care, it has come to refer to any strategy to increase the number of white or wealthy patients, while reducing the number of minority or poor patients.⁴¹⁸ This discussion of redlining is confined to the practice of excluding patients from health care services based on their community of residence.

Redlining in Managed Care and Home Health Agencies

Low-income and minority patients are perceived by many health care professionals as excessively costly to treat, rendering them less attractive to managed care organizations. To control the number of such members, managed care organizations use certain strategies that limit access of these groups, discourage them from applying for membership, or provide them with minimal service once they do enter the managed care organization.⁴¹⁹ Managed care organiza-

⁴¹⁷ See, e.g., Katy Chi-Wen Li, "The Private Insurance Industry's Tactics Against Suspected Homosexuals: Redlining Based on Occupation, Residence, and Marital Status," *American Journal of Law and Medicine*, vol. 22 (1996), p. 482. The phrase "medical redlining" originates from the home mortgage industry. It derives from a procedure in which lenders or insurers, in efforts to identify and eschew areas of high risk exposure, would enclose low-income, minority neighborhoods in red ink on local maps. The practice has also been associated heavily with the insurance industry. *Ibid.*

⁴¹⁸ See, e.g., "Richmond Blacks to Protest Kaiser's Medical Redlining," *Sun Reporter*, Aug. 27, 1998 (referring to the curtailment of emergency services by an HMO); "Medicare Plus Choice: Advocates Say Bulletin Confuses Seniors," *Health Line*, Nov. 9, 1998 (citing selective marketing techniques by managed care plans to attempt to enroll wealthy suburban seniors in medicare as medical redlining); Sabin Russell, "HMOs are Sacking Seniors," *San Francisco Chronicle*, Nov. 9, 1998, p. A-1 (citing selective marketing techniques by medicare HMOs as examples of medical redlining); Keith Henderson, "Health-Care Reform Raises Questions of Individual Rights," *Christian Science Monitor*, Mar. 29, 1994, p. 3 (defining redlining as "excluding people due to race, economic status, or medical condition"); "Groups Call for Sweeping Changes in Managed Care," *Medical Industry Today*, Dec. 4, 1997 (referring to redlining as a practice that places seniors and low-income populations at risk).

⁴¹⁹ Tactics used are: failure to include in the network the kinds of specialists needed by minorities, such as sickle-cell specialists; not offering prescription drugs often used by minority populations, such as methadone; minimizing the number of visitations allowed through delaying appoint-

⁴¹³ Raphael Metzger, "Hispanics, Health Care, and Title VI of the Civil Rights Act of 1964," *The Kansas Journal of Law and Public Policy*, vol. 3 (winter 1993-94), p. 35 (citing HHS, OCR, Proposed LEP Regulation, July 1991 (unofficial document)).

⁴¹⁴ Metzger, "Hispanics, Health Care," p. 35.

⁴¹⁵ However, OCR should not incorporate into its final rule the section of this draft regulation that requires a limited-English-proficient population to comprise 10 percent of the general population in order to be defined as a "substantial non-English Language Group." See Metzger, "Hispanics, Health Care," p. 35 (citing HHS, OCR, Proposed LEP Regulation, July 1991 (unofficial document), § 80.23(b)).

⁴¹⁶ O'Brien and Mackey interview, p. 7.

tions have neglected to invite into their provider networks many physicians and hospitals that treat large numbers of poor and minority patients.⁴²⁰ If a provider is located in an inner-city area, that physician or facility is more likely to be left out of the network. Medical redlining by managed care organizations is closely related to other discriminatory strategies employed by these organizations, such as selective marketing (also called "cherry-picking"), differential standards of care, and segregation of provider lists.⁴²¹

Medical redlining, although associated most strongly with managed care, also exists in other health care settings, such as home health agencies.⁴²² Home health agencies, which provide health care to patients in their homes, are peripheral to the mainstream health care industry and still governed by civil rights laws if they receive Federal funds. For example, OCR recently investigated a case in which a home health agency refused to serve patients who lived in federally subsidized housing projects and other inner-city areas.⁴²³ The agency justified its actions by citing policies for the protection of employees. OCR determined that there were less discriminatory alternatives than simply refusing to provide service to the redlined areas.⁴²⁴ OCR eventually negotiated a settlement agreement with the agency in which it agreed not to refuse or limit services to persons based on residence in certain areas, except in individualized cases, using well-defined standards and procedures for

determining safety risk. In the course of investigating that home health agency, OCR became aware that several agencies in the same area were operating with similar policies, which suggests that there may be hundreds more nationwide. Because they are on the periphery of core health care service providers, many of these agencies may be uncertain about the nature of their nondiscrimination obligations.

OCR Guidance on Redlining

In light of the number of home health agencies that may be practicing redlining, and the concern expressed by several regional office staff that OCR should be doing more in this area,⁴²⁵ it would be beneficial for OCR to develop and disseminate a comprehensive policy guidance in the form of published guidelines or a policy document. Published OCR guidance would provide notice to home health agencies that denying coverage based upon location of residence may violate Federal nondiscrimination laws. A guidance document could also describe in detail the specific policies and procedures that unlawfully discriminate, and enumerate alternative nondiscriminatory measures that may further the agency's objectives.

OCR has made a modest attempt to do this with its internal investigative guidance document. After agreements were reached on the redlining cases mentioned above, OCR issued a policy document to the regional offices about the problem of redlining by home health agencies. On its internal Web site the office published a 3-page document that recounts the investigation, analyzes the statistical data, applies the disparate impact standard to the justification supplied by the agency, and outlines the terms of settlement of one of the cases.⁴²⁶ It also offers tips for factfinding in future cases. While most of the information in the document appears useful, aspects of the issue require further clarification.

The discussion of the facts in the case provides OCR staff with enough background information to understand the dynamics behind a home health agency's decision to restrict its

ments; and aggressively marketing in wealthier, white suburban neighborhoods, but not marketing at all in the inner city. Lado interview, p. 26.

⁴²⁰ Editor, *Harvard Law Review*, "Impact of Managed Care," pp. 1628-29. See generally Rosenbaum et al., "Civil Rights in a Changing Health Care System."

⁴²¹ See Managed Care section above.

⁴²² See OCR findings detailing medical redlining practices of several home health agencies (e.g., Caroline Chang, regional manager, Region I, OCR, HHS, letter to Joanne Walsh, president and chief executive officer, Visiting Nurse Association of South Central Connecticut, Inc., New Haven, CT, July 7, 1998 (re: complaint no. 01-96-7801), and attached resolution agreement between the HHS, OCR, Region I, and Visiting Nurse Association of South Central Connecticut, Inc.; Chang letter, May 19, 1995 and Resolution Agreement re: 01-94-3050, respectively.

⁴²³ See generally OCR, "Restricted Service Area." The case involved a home health agency called Staff Builders. See chap. 4, for further details.

⁴²⁴ *Ibid.*, p. 2.

⁴²⁵ See Freeman interview, p. 3; Pollack interview, p. 8; Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, telephone interview, Feb. 10, 1999, p. 3 (hereafter cited as Kyle-Holmes interview); Halverson interview, p. 3.

⁴²⁶ See generally OCR, "Restricted Service Area."

service area.⁴²⁷ For example, the document stated that in the 1993 case, the basis for refusing to serve the area in which the complainant lived was safety. The agency had produced a manual enumerating safety guidelines that classified certain streets and housing complexes by degree of safety risk, as determined by agency staff. The most dangerous areas were designated "No Visits at Anytime." A second category contained areas that "were known to pose extraordinary risk later in the day" and thus no visits were allowed there after 1:00 p.m.⁴²⁸

The OCR document also details the data analysis used to determine if discrimination existed.⁴²⁹ The methodology was typical for denial of access cases. The regional office acquired census block and tract data and compared the racial composition of the tracts whose home health services were restricted with the tracts that received full services, finding that the policy affected a disproportionate number of minorities. This section of the document provides investigators with an example of the kind of analysis appropriate for these cases.

The document next applies the health care justification standard to the agency's safety justification.⁴³⁰ However, this discussion is not adequate. The document concludes that the agency's justification is insufficient because there are less discriminatory means of maintaining the employees' safety, but does not describe any of these means.⁴³¹ In its discussion of the terms of the settlement agreement, the document suggests that there are instances in which denial of services for safety reasons would constitute a legitimate justification. However, it stops short of listing the particular circumstances that would meet this burden.⁴³² This section should list procedures and criteria for agencies to use in determining whether an area meets the legal threshold of being too unsafe to serve.

The next section of the document identifies only two of the terms of the home health agency's settlement agreement with OCR, leaving out the other terms to which the agency

agreed.⁴³³ The investigators would have benefited from having access to the entire agreement, which could have been posted on the Intranet site as an addendum to the redlining document. The final section of the document identifies the types of information investigators should gather when investigating redlining cases. The document recommends reviewing the admission and termination policies for key words evidencing restrictions on service areas based upon safety guidelines; contacting State recipients that fund home health agencies and reviewing their regulations; checking the service area of the entity, looking for gerrymandering of minority areas; checking with referral sources to see whether they refer inner-city patients to home health agencies; getting information on local safety issues from local police; and checking the corporate structure of the agency to determine whether it is independent.⁴³⁴

The redlining investigative guidance document represents a good initial attempt to provide assistance to investigators on redlining. The information in the document is accurate and relevant. However, the document is inadequate in several respects. First, a comprehensive policy statement must address the recipient home health agencies as well as investigators. It must inform recipients of their obligations under title VI and the block grant nondiscrimination provisions. Further, with this document, OCR has not provided a set of guidelines or a policy document that would describe hypothetical situations that show denials of service constituting discrimination. Finally, the document is not organized in a way that makes explicit the issues, obligations, and procedures that affect recipients or investigators.

Despite its shortcomings, the guidance document does appear to touch on the paramount considerations of the redlining issue. It would benefit OCR to develop this document further by addressing recipients as well as investigators; restructuring the document into a more formal document; and adding a discussion of jurisdiction, examples of lawful and unlawful conduct, a safe harbor provision, and suggestions for data collection and analysis.

⁴²⁷ OCR, "Restricted Service Area," p. 1.

⁴²⁸ *Ibid.*

⁴²⁹ *Ibid.*, p. 2.

⁴³⁰ *Ibid.*

⁴³¹ *Ibid.*

⁴³² *Ibid.*

⁴³³ *Ibid.*

⁴³⁴ *Ibid.*, pp. 2-3.

Nursing Homes

Another issue that has gone largely unaddressed by OCR in recent years is title VI non-compliance in the nursing home context, particularly racial/ethnic segregation. Nonetheless, it appears that racial segregation in nursing homes is a prevalent problem affecting the national's health care system. Given that racial segregation is perhaps the most insidious form of discrimination, it seems that this phenomenon should be a focal point of OCR's civil rights enforcement activities. In particular, it would seem that OCR should provide policy guidance to nursing home recipients of HHS funds to ensure that each is aware of its title VI compliance responsibilities to ensure nondiscrimination on the basis of race, color, and national origin. The guidelines HHS does have for staff are extremely outdated and lack sufficient criteria and standards to measure compliance in the nursing home setting. The need for updated guidance for staff and recipients is borne out in examples of the serious nature of the segregation problem today. In addition, a comparison between the proactive responses undertaken by the legislative and judicial branches to the unfortunate lack of policy response by OCR illustrates a significant weakness in OCR's efforts to address one of the more glaring noncompliance issues present in the health care system, as well as more clearly demonstrating the need for new policy guidance from OCR.

According to one author, "Nursing homes are the most segregated publicly licensed health care facilities in the United States."⁴³⁵ Several authors have discussed the segregation of medicaid and non-medicaid patients, and the racial segregation of nursing home room assignments.⁴³⁶ For example, one study found that minorities experience longer delays than whites in being placed in nursing homes, even after controlling for factors such as sex, age, health conditions, special care requirements, and financ-

⁴³⁵ Randall, "Racist Health Care," p. 154.

⁴³⁶ David Falcone and Robert Broyles, "Access to Long-Term Care: Race as a Barrier," *Journal of Health Politics, Policy and Law*, vol. 19, no. 3 (fall 1994), p. 591; David Barton Smith, "Population Ecology and the Racial Integration of Hospitals and Nursing Homes in the United States," *Milbank Quarterly*, vol. 68, no. 4 (Dec. 22, 1990), p. 561; Smith, *Health Care Divided*, p. 317; Wallace et al., "Color-Blind Health Policy," p. 331; Watson, "Reinvigorating Title VI," pp. 941-42.

ing.⁴³⁷ A report of the New York State Advisory Committee to the Commission noted that although elder minorities are "among the most vulnerable members of society," they often face barriers in receiving health care and long-term care, such as in nursing homes.⁴³⁸

Segregation also is related to the costs of care; other forms of segregation involve the denial of medicaid patients, the separation of facilities for medicaid and nonmedicaid patients, or the displacement of patients once their private funding runs out and they are forced to rely on medicaid. Discriminating on the basis of socioeconomic status has an adverse affect on minority patients, who account for a large portion of those receiving medicaid. For example, limited bed certification is one way of denying access to and segregating nursing homes on the basis of socioeconomics.⁴³⁹ Under this practice, nursing homes can designate a certain number of beds that are certified to participate in the medicaid program. By limiting the number of medicaid patients they will accept, nursing homes can reserve more rooms for patients who have private sources of funding, on which the facilities make a greater profit.⁴⁴⁰ Similarly, beds can be declassified for medicaid use or patients can be reclassified as needing intermediate care and thus be dismissed from a nursing home, with the result of denying equal access to nursing home facilities.⁴⁴¹

Legislative and Judicial Response to Medicaid Discrimination by Nursing Homes

Discrimination in nursing homes has captured the attention of some courts and lawmakers. In 1983 Congress passed legislation to prevent medicaid cost shifting.⁴⁴² Hospitals were no

⁴³⁷ Falcone and Broyles "Access to Long-Term Care," p. 592.

⁴³⁸ New York State Advisory Committee to the USCCR, *Minority Elderly Access to Health Care and Nursing Homes*, November 1992, p. 48 (hereafter cited as NY SAC, *Minority Elderly Access*).

⁴³⁹ Randall, "Racist Health Care," p. 156.

⁴⁴⁰ *Ibid.*

⁴⁴¹ *Ibid.*, pp. 156-57.

⁴⁴² Social Security Amendments of 1983, Pub. L. No. 98-21, § 601, 97 Stat. 65, 149-63 (codified at 42 U.S.C. § 1395ww (1994 & Supp. II 1996)) (establishing prospective payment under which payments to hospitals are based on fixed cost estimates rather than on the actual cost of providing care). See also Smith, *Health Care Divided*, p. 255.

longer reimbursed by medicare based upon costs but were paid by the number of patients admitted and the types of illnesses treated.⁴⁴³ This law, which could potentially decrease profits associated with caring for backlogged patients, gave hospitals stronger incentives to place these patients in nursing homes.⁴⁴⁴

In 1990 a U.S. district court judge found that the "limited bed certification policy" developed by the State of Tennessee had an unjustified disparate impact on minorities, thus violating title VI.⁴⁴⁵ The court found that because of the greater existence of poverty in the State's black population, and because of that population's consequent dependency on medicaid, a policy that limits the number of nursing home beds disproportionately affects blacks.⁴⁴⁶ Although the precise holding only reaches the medicaid bed certification policy in one State, the reasoning may be extrapolated to prohibit any form of medicaid discrimination that has an unjustified disparate effect on minorities.⁴⁴⁷

Recent occurrences involving a nursing home chain have revealed that nursing homes may be summarily evicting medicaid patients to make room for private-pay patients.⁴⁴⁸ In response, the U.S. House of Representatives passed a bill in 1999 that would bar this practice.⁴⁴⁹ The bill would not force nursing homes to stay in the medicaid program, nor would it prevent them from restricting enrollment for new medicaid patients.⁴⁵⁰ It would simply prohibit these facilities from evicting patients who were already being treated, once the decision to discontinue

medicaid participation was made.⁴⁵¹ If passed by the Senate, this bill would overlap somewhat with two other statutes that reach medicaid discrimination: title VI of the Civil Rights Act and the Hill-Burton Act. Title VI jurisdiction in such cases would depend on whether the evictions had an adverse impact on minorities. Hill-Burton facilities, presumably, would already be prevented from such practices by the "third party payor programs" section of the act.⁴⁵²

In the view of one commentator, these legislative and judicial interventions caused State medicaid programs to search for innovative means of cost savings, such as taxing providers and using the extra revenue to draw down a larger Federal portion of the Federal-State matching program.⁴⁵³ Another cost-saving strategy involves medicaid managed care. With the recent influx of providers into the system, State medicaid programs have sought contracts that require MCOs to shoulder a significant portion of the financial risks associated with costly medicaid patients.⁴⁵⁴ This strategy has increased competition among MCOs and among nursing homes. The effect of this strategy on racial and ethnic minorities in nursing home care is uncertain; however, it is likely that long-term care increasingly will be provided in patients' homes by home health agencies.⁴⁵⁵ These agencies are also governed by title VI if the medicare home health benefit pays for their services. However, because the home health industry is new, its principal players may be unaware of the full extent of their nondiscrimination obligations.

⁴⁴³ Smith, *Health Care Divided*, p. 255.

⁴⁴⁴ *Ibid.*

⁴⁴⁵ *Linton v. Comm'r of Health and Env't*, 779 F. Supp. 925, 932, 935 (M.D. Tenn. 1990) (932, 935 (enjoining a policy that limited the number of hospital beds used by medicare beneficiaries)), *remanded*, 973 F.2d 1311 (6th Cir. Tenn. 1992), *subsequent appeal, aff'd, sub. nom.*, *Linton by Arnold v. Comm'r of Health and Env't*, 65 F.3d 508 (6th Cir. Tenn. 1995). Although this holding only affects the State of Tennessee, it establishes a strong precedent for other States. *Linton*, 779 F. Supp. at 935.

⁴⁴⁶ *Linton*, 779 F. Supp. at 932.

⁴⁴⁷ See Bonnyman interview, p. 8.

⁴⁴⁸ *Ibid.*

⁴⁴⁹ H.R. 540, 106th Cong., 2d Sess. (1999). See generally Sue Kirchoff, "Bill Would Bar Nursing Homes from Evicting Medicaid Patients," *Congressional Quarterly*, Mar. 13, 1999, p. 617 (hereafter cited as Kirchoff, "Nursing Home Bill").

⁴⁵⁰ Kirchoff, "Nursing Home Bill," p. 617.

OCR's Policy Development

OCR has addressed nursing home segregation to a limited extent through title VI guidelines relating to nursing homes and three internal policy memoranda.⁴⁵⁶ The guidelines and

⁴⁵¹ *Ibid.*

⁴⁵² 42 C.F.R. § 124.603(c) (1998).

⁴⁵³ See Smith, *Health Care Divided*, p. 256.

⁴⁵⁴ *Ibid.*

⁴⁵⁵ *Ibid.*, p. 275.

⁴⁵⁶ U.S. Department of Health, Education, and Welfare, OCR, "Guidelines for Compliance of Nursing Homes and Similar Facilities with title VI of the Civil Rights Act of 1964," November 1969 (hereafter cited as OCR, "Nursing Home Guidelines"); Wendy B. Pailen, acting director, Division of Standards and Policy Development, memorandum to Dewey E. Dodds, director, OCR, Region III, HHS, Feb. 6,

memoranda may have contributed somewhat to the body of reference for investigative and legal HHS staff, but were never published in the *Federal Register*.⁴⁵⁷ Consequently, OCR has failed to provide notice to nursing homes of their title VI responsibilities.

The outdated nursing home guidelines, issued in 1969, offer very little instruction on title VI. The guidelines do not provide background information, explore significant issues, or discuss legal developments affecting nursing home discrimination. Neither do they present hypothetical examples of discriminatory practices or acceptable alternative measures. However, the guidelines do identify seven functional areas in which nursing homes may not discriminate:

- *Admissions.* All residents must be admitted to the facility without discrimination; no inquiries may be made regarding race, color, or national origin before admission; the nursing home should use its referral sources such that those patients accepted by the nursing home reflect the racial and ethnic distribution of the service area; and where there is a significant disparity in racial or ethnic identity between the patient population and the service area, the nursing home must determine the reason and act to prevent it.
- *Records.* Records must be maintained without discrimination for all residents, and identification in the records of race, color, national origin may be used to demonstrate compliance with title VI.
- *Services and physical facilities provided.* Services and facilities, ranging from medical care to dining areas, must be provided to residents without discrimination.

1980 (re: policy clarification request—Elizabethtown Masonic Homes, case # 03-78-7049) (hereafter cited as Pailen memorandum); David F. Chavkin, deputy director for Program Development, memorandum to Carolyn Russell, regional director, Region IV, OCR, HHS, Dec. 11, 1980 (re: nursing home preferential admission) (hereafter cited as Chavkin memorandum, Dec. 11, 1980); David F. Chavkin, deputy director for Program Development, memorandum to Carmen Rockwell, acting director, Region III, OCR, HHS, Jan. 19, 1981 (re: nursing home admissions practices) (hereafter cited as Chavkin memorandum, Jan. 19, 1981).

⁴⁵⁷ Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 2.

- *Room assignment and transfers.* Residents are to be assigned to rooms, wards, floors, etc., without regard to race or ethnicity, and residents must not be asked whether they are willing to share accommodations with persons of different racial or ethnic backgrounds.
- *Attending physicians' privileges.* Privileges of attending residents must be awarded to physicians or other personnel without discrimination.
- *Notification of availability of services and nondiscrimination policy.* Nursing homes must effectively notify the community of their available services and nondiscrimination policy.
- *Referrals to other nursing homes.* Nursing homes may not refer patients in a discriminatory manner.⁴⁵⁸

OCR's three policy memoranda were issued between 1980 and 1981. The first offers policy clarification for a case involving race-based segregation of a Masonic nursing home.⁴⁵⁹ The issue was whether a desegregation plan affecting an all-white Masonic nursing home was legally supportable and feasible.⁴⁶⁰ However, in view of the rapid rate of development of desegregation case law, the issues articulated in this document may no longer be relevant.

The second memorandum addresses discrimination against medicaid beneficiaries.⁴⁶¹ This document adequately responds to the issue of when and how nursing homes violate title VI in refusing medicaid patients. The document provides concise statements of the issue and conclusion, as well as a discussion of the legal standard for proving impact discrimination, the legitimate objective test.⁴⁶² It then applies the standard to the hypothetical case of a nursing home that is attempting to save costs by avoiding what it perceives as insufficient medicaid reimbursement rates, stating that unless the

⁴⁵⁸ OCR, "Nursing Home Guidelines."

⁴⁵⁹ See generally Pailen memorandum.

⁴⁶⁰ *Ibid.*, pp. 1-2.

⁴⁶¹ See generally Chavkin memorandum, Dec. 11, 1980.

⁴⁶² *Ibid.*, pp. 1-2. See also Chavkin letter, p. 2 (identifying the legitimate objectives test as a method of justification for a recipient's discriminatory policy or practice). See also "Defining Disparate Impact Discrimination," above.

State's rate was unreasonably low, this method of cost savings would not qualify as a legitimate justification.⁴⁶³

The third memorandum concerns the title VI implications of religious-based discrimination by nursing homes.⁴⁶⁴ This document presents the issue and conclusion first, followed by a more detailed discussion in the contexts of religious and fraternal homes.⁴⁶⁵ According to the memorandum, the issue manifests itself when a nursing home rejects patients who do not practice a particular religion, and that religious discrimination has the effect of disproportionately blocking minority access. The memorandum affirms that it is not discrimination on the basis of religion that triggers title VI,⁴⁶⁶ but the effect of that lawful discrimination on minorities.⁴⁶⁷ Nonetheless, in the case of a bona fide religious home, the memorandum allows an exemption from the rigors of the title VI evidentiary framework.⁴⁶⁸ The framework must be followed, but the relevant service area population for purposes of determining whether minorities are disproportionately affected, is the population within the service area that belongs to the particular religious order, rather than the general population.⁴⁶⁹ This modification of the traditional framework makes a finding of a title VI violation much less probable. The memorandum contrasts the religious home situation with that of a fraternal organization home, finding that without the protection of the "free exercise" clause of the Constitution, the usual justification framework holds.⁴⁷⁰

Suggested Elements of Updated Guidelines

In view of the extent of segregation in the industry, nursing home operators, OCR investigators, and patients would benefit from updated,

⁴⁶³ *Ibid.*, p. 2.

⁴⁶⁴ Chavkin memorandum, Jan. 19, 1981.

⁴⁶⁵ *Ibid.*, p. 2.

⁴⁶⁶ *Ibid.*, p. 1 (citing the legislative history of title VI).

⁴⁶⁷ *Ibid.*

⁴⁶⁸ See "Discriminatory Practices Defined," above, for a discussion of the title VI evidentiary framework, and the standards used by courts to assess a recipient's justification for its discriminatory health care policies or practices. See also Chavkin letter, p. 2 (delineating the legitimate objective test).

⁴⁶⁹ Chavkin memorandum, Jan. 19, 1981, p. 1.

⁴⁷⁰ *Ibid.*, p. 3.

expanded, and published guidelines on the application of civil rights laws and regulations to the industry. These guidelines should include a background section outlining the nondiscrimination mandate of title VI, and its jurisdiction. This section should state that any nursing home that receives funds from medicare, medicaid, or any other Federal program, must abide by title VI. It should also outline the evidentiary burdens and legal standards used in determining whether a violation has occurred. Finally, the introduction should contain a narrative on the issue of nursing home segregation, including its history, causes, and relevant case law, such as *Linton v. Commissioner*.⁴⁷¹

The substantive section of the guidelines could remain divided into the seven functional areas identified in the 1969 guidelines, with certain adjustments. Each requirement should contain descriptions and examples of prohibited conduct and, if appropriate, acceptable alternatives. For example, the admissions requirement should state that discrimination against medicaid beneficiaries, by limiting the number of medicaid-certified beds, or through other tactics that delay or prevent medicaid beneficiaries from being placed in nursing homes, triggers title VI jurisdiction. The services and facilities measure could be adjusted so as to decrease the space devoted to the prevention of physical segregation, while according new emphasis on equal medical treatment. For example, the section could state that two patients with the same set of symptoms and medical history must receive the same examination, diagnosis, and treatment regardless of race or ethnicity. Further, the referral provision could be expanded to include examples of discriminatory referrals based upon race or method of payment, such as the transfer of a patient to another facility based upon the down-grading of the patient's required level of care, and the consequent lower reimbursement. Finally, a section describing the application of title VI to religious and fraternal organization nursing homes would benefit these types of recipients. This section could be modeled after the 1981 policy memorandum.⁴⁷²

The final section of the guidelines could discuss enforcement by OCR. This section would

⁴⁷¹ *Linton*, 779 F. Supp. at 925, 932 (M.D. Tenn. 1990).

⁴⁷² See Chavkin memorandum, Jan. 19, 1981.

describe the procedures that OCR follows in determining whether a violation exists or when doing a compliance review. It could cite examples of potential violations and suggest the types of data to be gathered, statistical computations to be performed, witnesses and experts to be interviewed, etc. It could also explain the phases of the voluntary compliance process. The enforcement section might also address fund termination for noncompliant nursing homes.

Adoption and Foster Care

OCR's recent title VI policy development record is somewhat stronger with respect to title VI-related issues outside the health care context. For example, OCR has worked in partnership with Administration for Children and Families to issue a recent policy guidance⁴⁷³ to assist public and private agencies receiving Federal assistance that are involved in adoption or foster care placements in complying with title VI and nondiscrimination requirements of the Multiethnic Placement Act of 1994 (MEPA).⁴⁷⁴ This policy guidance addresses title VI issues in the context of social services. However, OCR has issued no policy guidance addressing health care related issues and title VI in a number of years.⁴⁷⁵ The MEPA guidance is therefore the only policy guidance OCR has developed that addresses title VI issues from a current perspective.

⁴⁷³ HHS, OCR and HHS, Administration for Children and Families, OCR, "Policy Guidance on the Use of Race, Color, National Origin as Considerations in Adoption and Foster Care Placements," undated.

⁴⁷⁴ Pub. L. No. 103-382, title V, § 553, 108 Stat. 4056, repealed by Pub. L. No. 104-188, title I, § 1808(d), 110 Stat. 1904 (codified at 42 U.S.C. § 1996b (Supp. II 1996)). The new law contains nondiscrimination requirements similar to those contained in the MEPA. It states, "A person or government that is involved in adoption or foster care placements may not deny to any individual the opportunity to become an adoptive or a foster parent, on the basis of the race, color, or national origin of the individual, or of the child, involved." 42 U.S.C. § 1996b(1)(A) (Supp. II 1996). It further states that "[n]oncompliance with paragraph (1) is deemed a violation of title VI of the Civil Rights Act of 1964." 42 U.S.C. § 1996b(2) (Supp. II 1996) (citation omitted).

⁴⁷⁵ Although OCR issued guidance on title VI as it relates to patients with limited English proficiency in 1998, OCR considers this document "investigative" and not actual "policy" guidance. The Commission, however, believes that the distinction is not an important one since investigative guidance has to address policy issues in some fashion.

Minority Participation in Clinical Trials

OCR has not addressed minority participation in clinical trials in title VI policy guidance, and the lack of participation may be directly related to policies and practices of federally assisted research programs. The ability of title VI enforcement to address the lack of minority participation in clinical trials is an avenue OCR has not explored. The lack of minority participation in clinical research trials has generated significant concerns centering on adverse effects on minorities and women of using only white males as research subjects.⁴⁷⁶ Commentators, including HHS agencies, have reported on the need to ensure inclusion of minorities and women in clinical trials.⁴⁷⁷ For example, several commentators have illustrated this need by reporting on findings indicating differences in disease susceptibility and response to treatment across racial/ethnic lines. They reported that African Americans respond differently from whites to angiotensin converting enzyme (ACE) inhibitors; subpopulations among Asians have been found to respond differently to psychiatric medication—in particular, Chinese patients are more susceptible to Haloperidol than white patients and Japanese patients require lower doses of Chlorpromazine; and the prevalence of low-birthweight infants differs markedly among Hispanic subgroups.⁴⁷⁸

Elsewhere, another commentator has concluded:

Although researchers offer a number of possibly valid reasons for excluding women from clinical studies . . . no such justifications exist for excluding African-Americans and other minorities from biomedical research populations. On the contrary, scientific re-

⁴⁷⁶ See USCCR, *The Health Care Challenge*, vol. I, chap. 2.

⁴⁷⁷ See Barbara A. Noah, "Racial Disparities in the Delivery of Health Care," *University of San Diego Law Review*, vol. 35, no. 1 (winter 1998), p. 152; Lisa C. Ikemoto, "The Fuzzy Logic of Race and Gender in the Mismeasure of Asian American Women's Health Needs," *University of Cincinnati Law Review*, vol. 65 (1997), p. 799; Judith H. LaRosa, Belinda Seto, Carlos E. Caban, and Eugene G. Hayunga, "Including Women and Minorities in Clinical Research," *Applied Clinical Trials*, vol. 4, no. 5 (May 1995), p. 31 (hereafter cited as LaRosa et al., "Including Women and Minorities in Clinical Research"); 60 *Fed. Reg.* 47,947 (1995); see also USCCR, *The Health Care Challenge*, vol. I, chap. 2, for a discussion on clinical trials from a social science perspective.

⁴⁷⁸ LaRosa et al., "Including Women and Minorities in Clinical Research," p. 33.

search has documented the wide variation of the pharmacokinetic effects of drugs across racial and ethnic lines. One cannot, therefore, safely extrapolate from data based on white males to others in the population.⁴⁷⁹

Moreover, the Centers for Disease Control (CDC), an HHS operating division, has stated in its guidelines on the inclusion of minorities and women that the underrepresentation of racial and ethnic minorities in research “has resulted in significant gaps in knowledge about the health of racial and ethnic minority populations and their responses to interventions.”⁴⁸⁰

Because of these concerns, several HHS organizations have issued guidelines on inclusion of women and minorities in clinical trials.⁴⁸¹ For example, in March 1994, the National Institutes of Health (NIH) issued guidelines⁴⁸² requiring applicants for clinical trials either to include minorities and women as research subjects in their studies or show a “clear and compelling” rationale for failing to do so, which updated earlier policy issued in 1990.⁴⁸³ The new guidelines implemented a statute enacted in 1993, the NIH Revitalization Act,⁴⁸⁴ which directed NIH to provide guidelines for including women and minorities in clinical research.⁴⁸⁵ The guidelines require that:

- Minorities and women and their subpopulations be included in all NIH-supported biomedical and behavioral research involving human subjects.
- Women and minorities be included in all Phase III (later stage) clinical trials in numbers adequate to allow for valid analyses of differences in intervention effect.

⁴⁷⁹ Noah, “Racial Disparities in the Delivery of Health Care,” p. 153 (citations omitted).

⁴⁸⁰ 60 Fed. Reg. at 47,948.

⁴⁸¹ See, e.g., 59 Fed. Reg. 14,508 (1994); 60 Fed. Reg. 47,948 (guidelines issued jointly by CDC and the Agency for Toxic Substances and Disease Registry (ATSDR)).

⁴⁸² 59 Fed. Reg. 14,508.

⁴⁸³ See National Institutes of Health, “Policy Concerning the Inclusion of Women in Study Populations,” and “Policy Concerning the Inclusion of Minorities in Study Population,” *NIH Guide for Grants and Contracts*, 1990.

⁴⁸⁴ Pub. L. No. 103-43, 107 Stat. 122 (codified in scattered sections of 8, 21, and 42 U.S.C. (1994 & Sup. II. 1996)).

⁴⁸⁵ 42 U.S.C. § 289a-2(d) (1994 & Supp. II 1996).

- Cost is not allowed as an acceptable reason for excluding these groups.
- NIH initiate programs and support for outreach efforts to recruit and retain minorities and their subpopulations as volunteers.⁴⁸⁶

The 1994 guidelines are lengthy and address several factors that play a role including minorities and women in clinical trials. These include funding; implementation; the role of peer review groups; recruitment and outreach by NIH extramural and intramural investigators; educational outreach by NIH to inform the professional community; and definitions of key terms, such as “clinical trial,” “valid analysis,” and “significant difference.”⁴⁸⁷ For example, the guidelines define valid analysis as an “unbiased assessment” requiring “[a]llocation of study participants of both genders and from different racial/ethnic groups to the intervention and control groups by an unbiased process such as randomization.”⁴⁸⁸ The guidelines explain these terminologies from a scientific perspective, not from a civil rights perspective. For example, the guidelines call for “unbiased” analysis and define it in terms of a scientific process; there is no guidance from a more human or “real-world” perspective offering standards to determine whether there is any racial or gender bias in the actual implementation of the program.⁴⁸⁹

In September 1995, two other HHS operating divisions, the Centers for Disease Control, and the Agency for Toxic Substances and Disease Registry (ATSDR), issued policy guidelines on the inclusion of women and minorities in externally awarded research.⁴⁹⁰ These guidelines apply to all CDC externally awarded research regardless of the mechanism of financial support, whether grant, cooperative agreement, contract, purchase order, or other funding.⁴⁹¹ Like the NIH guidelines, the CDC guidelines require that women and members of racial and ethnic minorities be included in all studies involving hu-

⁴⁸⁶ 59 Fed. Reg. 14,508.

⁴⁸⁷ *Id.* at 14,509-14,511.

⁴⁸⁸ *Id.* at 14,511.

⁴⁸⁹ *Id.* at 14,512.

⁴⁹⁰ 60 Fed. Reg. 47,947 (1995).

⁴⁹¹ *Id.* at 47,948.

man subjects, "unless a clear and compelling rationale and justification to the satisfaction of CDC that inclusion is inappropriate or clearly not feasible."⁴⁹²

The requirements contained in these guidelines appear strong enough to encourage inclusion of minorities and women in research programs assisted by HHS. However, although the guidelines proscribe activities that could result in discrimination against women and minorities in clinical trials, they do not address the sanctions that would be applied to research programs that failed to meet these requirements. This is where a civil rights enforcement component to complement the proscriptions and ensure compliance would seem appropriate. OCR has expressed concern about minorities' and women's participation in clinical trials, and OCR staff acted to ensure that the 1994 HHS strategic plan would embrace the issue.⁴⁹³ However, OCR has not incorporated the inclusion issue into its enforcement regime.⁴⁹⁴ NIH collaboration with OCR to address potential title VI, Hill-Burton, or title IX compliance issues associated with failure to comply with these guidelines and jointly issued guidance to research programs receiving HHS funds also could assist recipients with compliance.

Overall, it appears that OCR has never explored in policy guidance the extent to which lack of minority participation in clinical research trials implicates title VI, Hill-Burton, or other civil rights provisions requiring nondiscrimination on the basis of race. However, although OCR has not developed guidance on these issues, it is clear that civil rights related concerns motivated NIH and other HHS operating divisions engaging in clinical research to develop guidelines requiring minority and female inclusion in clinical research trials. It appears that, given the many clinical research projects being conducted by federally assisted programs across the country, some guidance from OCR to recipients conducting such research would be beneficial to recipients and beneficiaries alike. In particular, research programs receiving Federal funds

would be reminded of their responsibilities to comply with title VI and would be provided with examples of noncompliance with the statute in the context of medical research. Moreover, by issuing some form of guidance, OCR can better ensure recipients understand that failure to include minorities and/or women can result in a violation of Federal civil rights law.

Staff Privileges

Historically, hospitals have screened out minority and poor patients through three main strategies: denying access based upon method of payment; failing to provide cultural, linguistic, or other accommodations for the poor and minorities; and limiting the number of physicians on staff that treat minorities.⁴⁹⁵ Discrimination against minority physicians has been one of the most successful of the three approaches.⁴⁹⁶ Traditionally it was accomplished through the denial of staff privileges, which confer the right to admit patients and practice medicine at a hospi-

⁴⁹⁵ Rosenbaum and Shin, "Medicaid Managed Care," p. 27. See generally Rosenbaum, et al., "Civil Rights in a Changing Health Care System." According to one scholar, discrimination by hospitals dates back to the transformation of the hospital in the late 19th century. Before the introduction into medicine of sophisticated technologies, patients that could afford private physicians paid for house calls. There were few medical institutions, other than a handful of public or philanthropically funded facilities in large cities. These facilities mostly served poor and minority patients. Physicians cared for the poor mainly as a form of charity, while earning their livings by treating affluent patients in their private homes. Technological advancements such as anesthesia brought about new methods of diagnosis, testing, and treatment. As physicians began to use these new technologies, house calls became less frequent, and the hospital supplanted the private home as the place of treatment for those who could afford it. Thus, the character of hospitals changed dramatically, from nonprofit, philanthropic facilities, to for-profit ventures. As hospitals became necessary to the successful practice of medicine, medical staffs became increasingly powerful and exclusive. These staffs sought to prevent minority and ethnic physicians from using the hospital facilities to treat their patients. This transformation coincided with the passage of Jim Crow laws, which legitimated overt segregation. Smith, *Health Care Divided*, pp. 11-16.

⁴⁹⁶ Examples of the first strategy include hospitals or physicians refusing to treat or limiting the number of medicaid patients, and requiring an advance deposit before treating patients. The second tactic involves requiring all medical appointments to be made by telephone, failing to provide language interpreters for limited-English-proficient patients, or using outright intimidation. See generally Rosenbaum et al., "Civil Rights in a Changing Health Care System."

⁴⁹² *Id.* at 47,949.

⁴⁹³ Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 3.

⁴⁹⁴ See *ibid.*

tal or other health care facility.⁴⁹⁷ After the civil rights movement and laws and court decisions that made segregation illegal, hospitals looked for indirect means of avoiding minority patients.⁴⁹⁸ The hospital would establish a policy whereby only patients whose physicians held staff privileges would be accepted. It would then select staff physicians based upon criteria that would screen out racial and ethnic minorities, such as membership in a local medical association or board certification.⁴⁹⁹ This practice continues today.⁵⁰⁰

With the evolution of managed care organizations, discrimination against minority physicians has expanded to include not only minority physicians but those who traditionally serve poor and minority patients.⁵⁰¹ Managed care organizations discriminate against physicians because these organizations emphasize cost savings.⁵⁰² Although the motive differs, the approach is fundamentally

⁴⁹⁷ Clinical staff privileges are defined by the Joint Commission on the Accreditation of Hospitals as “[p]ermission to provide medical or other patient care services in the granting institution, within well-defined limits, based on the individual’s professional license and his experience, competence, ability and judgment.” Karen G. Seimetz, “Medical Staff Membership Decisions: Judicial Intervention,” *University of Illinois Law Review*, 1985, p. 473, n. 1 (citing Joint Commission on the Accreditation of Hospitals, *Accreditation Manual For Hospitals/1985*, 1984, p. 217). See also John J. Smith, “Specialty Board Certification and Federal Civil Rights Statutes,” *Journal of Contemporary Health Law & Policy*, vol. 11 (fall 1994), p. 116.

⁴⁹⁸ See, e.g., title VI of the Civil Rights Act of 1964 (codified at 42 U.S.C. § 2000d (1994)); the Hospital Survey and Construction Act, Pub. L. No. 79-725, 60 Stat. 1040 (codified as amended at 42 U.S.C. §§ 291-291o-1 (1994)); *Simkins v. Moses Cone Memorial Hosp.*, 323 F.2d 959 (4th Cir. 1963) (en banc), cert. denied, 376 U.S. 938 (1964).

⁴⁹⁹ Rosenbaum and Shin, “Medicaid Managed Care,” p. 27. See also Randall, “Clinton’s Health Care Reform Proposal,” pp. 224, 230.

⁵⁰⁰ See Editor, *Harvard Law Review*, “Impact of Managed Care,” pp. 1630-31 (citing W. Michael Byrd et al., “African-American Physicians’ Views on Health Reform: Results of a Survey,” *Journal of the National Medical Association*, vol. 86 (1994), p. 192).

⁵⁰¹ Such physicians tend to be minorities themselves. See USCCR, *The Health Care Challenge*, vol. I, chaps. 2-3; Editor, *Harvard Law Review*, “Impact of Managed Care,” pp. 1630-31. See also Rosenbaum and Shin, “Medicaid Managed Care,” p. 28. See generally Rosenbaum et al., “Civil Rights in a Changing Health Care System.”

⁵⁰² See Rosenbaum and Shin, “Medicaid Managed Care,” pp. 23-24; Editor, *Harvard Law Review*, “Impact of Managed Care,” p. 1628; Randall, “Clinton’s Health Care Reform Proposal,” p. 230. See generally Rosenbaum et al., “Civil Rights in a Changing Health Care System.”

similar. Some of the methods that may be used to filter out these physicians are: (1) rejecting applicants who accept medicaid; (2) requiring board certification or membership in a local medical association; (3) excluding from their networks hospitals and physicians’ offices located in poorer areas; (4) restricting physicians to membership in limited-purpose networks, such as those that only allow referrals from physician groups dedicated to serving publicly funded patients; and (5) subjecting physicians’ records to post-treatment utilization review.⁵⁰³

Although the rationales for their discriminatory conduct differ, both hospitals and MCOs violate title VI if the disparate effects of their policies cannot be legally justified.⁵⁰⁴ Further, because MCOs select hospitals and physicians for their networks based on cost effectiveness, hospitals may soon adopt similar cost-saving strategies so as to be more attractive to MCO networks. This could lead to utilization review by hospital staffs in their own evaluation and selection of physicians. Physicians whose costs are higher may be rejected on that basis from hospital staffs as well as provider networks.

Guidelines Proscribing Discrimination Against Physicians

OCR has addressed staff privileges in three external policy guidance documents, for hospitals, for nursing homes, and questions and answers on title VI, all disseminated in November of 1969.⁵⁰⁵ An internal memorandum that included a brief discussion of staff privileges was issued in

⁵⁰³ See generally Rosenbaum et al., “Civil Rights in a Changing Health Care System,” p. 90. See also Randall, “Clinton’s Health Care Reform Proposal,” pp. 230-31; Marsha Gold, Lyle Nelson, Timothy Lake, Robert Hurley, and Robert Berenson, “Behind the Curve: A Critical Assessment of How Little is Known About Arrangements Between Managed Care Plans and Physicians,” *Medical Care Research and Review*, vol. 52, no. 3 (September 1995), p. 317.

⁵⁰⁴ In addition to title VI, the Hill-Burton Act prohibits Hill-Burton facilities from discrimination in the forms of denial of staff privileges and refusal to accept medicaid. 42 C.F.R. § 124.603 (c), (d) (1998).

⁵⁰⁵ U.S. Department of Health, Education, and Welfare, OCR, “Guidelines for Compliance of Hospitals with Title VI of the Civil Rights Act of 1964,” November 1969 (hereafter cited as OCR, “Hospital Guidelines”); OCR, “Nursing Home Guidelines,” U.S. Department of Health, Education, and Welfare, OCR, “Title VI of the Civil Rights Act of 1964 Questions and Answers,” (hereafter cited as OCR, “Title VI Q & A”). The nursing home guidelines are discussed above in the section on nursing homes.

1972.⁵⁰⁶ The hospital guidelines include a paragraph devoted to staff privileges, which is earnest in spirit, if somewhat lacking in substance. The focus is on discrimination against minority physicians, which would perhaps have been adequate for the time.⁵⁰⁷ However, the provision would have been more comprehensive had it articulated the links between the representation of minorities on medical staffs and access to quality care for minorities.⁵⁰⁸ The paragraph included the following provisions:

Staff privileges . . . in all areas and specialties are granted, maintained, upgraded and withdrawn in a nondiscriminatory manner, and standards for professional qualification are applied uniformly without regard to race, color, or national origin. No requirement for membership in an organization may be established if at the time covered by such requirement the organization discriminated Restrictions on the granting of staff privileges are not applied so as to perpetuate past discrimination. For example, if a hospital which formerly admitted general practitioners but excluded minority group physicians from its staff, subsequently adopted a policy restricting staff privileges to specialists, while retaining general practitioners already on staff, it must admit any practitioner who would have been qualified were it not for that practitioner's race, color, or national origin.⁵⁰⁹

The question and answer document offers more detailed guidance on minority physician

⁵⁰⁶ Patricia A. King, deputy director, OCR, U.S. Department of Health, Education, and Welfare, memorandum to Louis H. Rives, Jr., director, Health and Social Services Division, Department of Health, Education, and Welfare, Apr. 14, 1972 (re: relationship between title VI and practices of physicians).

⁵⁰⁷ OCR, "Hospital Guidelines."

⁵⁰⁸ The authority for this particular guideline was presumably based upon 45 C.F.R. § 80.3 (b) (2), the regulation's blanket prohibition against any policy that has the effect of creating a disproportionate adverse impact on the beneficiary population. Since physicians with staff privileges usually maintain a contractual relationship with their hospitals, these physicians would not be protected by the employment practices provision of the regulations. See *Diggs v. Harris Hospital-Methodist*, 847 F.2d 270 (5th Cir. 1988), *cert. denied*, 488 U.S. 956 (1988) (finding that an African American physician was not an employee of a hospital denying him staff privileges).

⁵⁰⁹ OCR, "Hospital Guidelines." The nursing home guidelines section on staff privileges is somewhat smaller. It reads: "Attending Physicians' Privileges: Privileges of attending residents in the nursing home are granted to physicians and other health professionals without discrimination." *Ibid.*

discrimination. It is divided into three parts: general questions; hospitals, nursing homes, and similar facilities; and health and social service agencies.⁵¹⁰ The document provides the following examples of discrimination in hospital staff privileges:

- In a community in which there are minority general practitioners a hospital which formerly admitted general practitioners but excluded minority group physicians from staff subsequently adopts a policy restricting staff membership to specialists while retaining general practitioners already on staff.
- A hospital requires that staff physicians have interned or served their residencies at the hospital but the hospital has never had minority group residents or interns.
- Minority staff physicians are denied participation in all aspects of staff privileges including upgrading available to other physicians.
- A hospital states that its staff is closed and no additional physicians will be admitted to staff privileges but makes exceptions to that policy which have the effect of admitting nonminority group physicians.⁵¹¹

The objective of these policy documents was clearly to end discrimination against minority applicants to medical staffs. The guidelines were never published,⁵¹² and are now almost 30 years old. Further, they provide little title VI background information, and their discussions of prohibited activities are not detailed. In addition, the documents fail to acknowledge the correlation between the adequate representation of minority physicians on staffs and networks, and equal access to quality health care for minority patients—the link that provides title VI regulatory jurisdiction.⁵¹³

⁵¹⁰ OCR, "Title VI Q & A."

⁵¹¹ *Ibid.*

⁵¹² Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 2.

⁵¹³ 45 C.F.R. § 80.3(b)(2) (1998). Since medical staffs are not employed by hospitals, generally, but contract with them, the employment discrimination of title VI would not reach physicians denied staff privileges. Moreover, the guidelines preventing discrimination against minority physicians were developed before 45 C.F.R. § 80.3(c)(3), the employment provision of the title VI regulations which was amended on July 5,

Surely, in 30 years OCR could have developed further insight into how to identify and prevent discrimination against minority physicians and the patients they serve. The most glaring example of OCR's failure to keep up with changes in health care is its failure to publish any guidelines for managed care organizations, which now provide health coverage for the majority of Americans. If managed care is really one of OCR's top priorities, as claimed in its strategic plan,⁵¹⁴ it is paramount that OCR develop and publish title VI guidelines for MCOs in the *Federal Register*. These guidelines should include a section on physician discrimination.

Need for Additional Guidelines

The elimination of discrimination against minority physicians and the patients they serve, mandates proactive leadership by OCR. That office must be willing to educate the public, recipients, and its own staff on how to recognize and cease such conduct. Publishing separate guidelines for hospitals, managed care organizations, and other potential discriminators, is an important first step. OCR could contribute toward achieving the goal of nondiscrimination against minority physicians and their patients by improving its existing hospital and nursing home guidelines, as well as developing new guidelines for managed care organizations. The guidelines should focus on all forms of discriminatory conduct by these entities, including discrimination against physicians. In general, each set of guidelines would benefit from a short introductory section that explained title VI in relation to the health facility or MCO. The background section should describe the problem, articulate the purpose of the guidelines, and elucidate the importance of increasing the number of minority physicians so as to improve access to quality health care among minorities. It should also briefly explain the jurisdiction, standards, evidentiary burdens, and general enforcement procedures associated with title VI, the Hill-

1973, to reach beyond programs designed for the purpose of employment or training. See Peter E. Holmes, director, OCR, U.S. Department of Health, Education, and Welfare, memorandum to Theodore A. Miles, assistant general counsel, GCR, Oct. 30, 1973 (re: effect of title VI on employment practices in health and social service programs).

⁵¹⁴ For detailed discussion of OCR's strategic plan, see chap. 2.

Burton act, and the nondiscrimination provisions of certain block grants.

Of particular importance in the general section would be a description of how the statistical disparate effects analysis is conducted. The section could explain that analysis is made by examining the service area out of which the complaint originated. The statistically significant disparity is measured in relation to the area in which the defendant provides its services, offers its benefits, or conducts its business. It would offer examples, such as the following: if a complainant were to allege a discriminatory denial of staff privileges by a hospital whose service area covers a county, then disparate impact against minorities presumably would be measured by comparing the facility's inpatient census against the proportion of racial or ethnic minority persons residing or using health care services in the county.⁵¹⁵

Each set of new or improved guidelines should list prohibited activities, such as those identified in the question and answer document. In addition to those, certain practices might be added, with a qualification that the practices only violate title VI if they affect minority patients disproportionately and fail to meet the health care necessity standard.⁵¹⁶ These include such requirements for medical staff or network membership as: (1) nonacceptance of medicaid patients, (2) board certification, (3) membership in a local medical association, (4) low resource consumption patterns, and (5) location of outpatient office in a predominately white area.

The new guidelines should also outline permitted practices, or contexts in which some of the above practices would be permissible. The document could emphasize that health facilities and MCOs may take certain factors into consideration, such as board certification or resource

⁵¹⁵ See generally Rosenbaum et al., "Civil Rights in a Changing Health Care System."

⁵¹⁶ See "Defining Prohibited Discriminatory Practices" above for a discussion of the recommended "health care necessity" standard. Under this standard, a recipient would have to show that its challenged policy or practice must significantly further an important health care objective. It is unclear what the current standard applied by OCR is, although a policy letter issued in 1981 appears to use a "legitimate objective" test, which asks whether the health entity's justification for discrimination is necessary to further a legitimate objective that is unrelated to race, color, or national origin. See Chavkin letter, p. 2, item 2, "Compliance Standard."

consumption patterns, so long as they do not create disparate effects. Further, the guidelines should state that even if these considerations do create disparate effects, it may still be lawful to incorporate them into the selection process, as long as they meet the health care necessity standard.⁵¹⁷

Finally, each of the minority physician non-discrimination provisions of the guidelines should include examples detailing the kinds of prohibited practices, the information collected in an investigation, the legal standards and evidentiary burdens applied in each case, potentially less discriminatory alternatives, and procedures for seeking voluntary compliance. For example, one hypothetical example might include an MCO that rejected a physician based upon high resource consumption patterns. The guidelines would explain how such a case would be approached by OCR.⁵¹⁸ This section would serve to educate both recipients and investigators as to context-specific considerations of the investigation and enforcement processes relating to physician discrimination cases.

Organ Transplantation

An aspect of health care inequality that thus far seems to have eluded OCR's attention concerns organ donation and transplantation. A shortage of available cadaveric organs,⁵¹⁹ such as kidneys, hearts, livers, and pancreases, has made obtaining needed organs difficult for all patients, regardless of race.⁵²⁰ However, in many

cases, blacks suffer disproportionately from the dearth of donor organs.⁵²¹ A 1991 report noted that blacks waited twice as long as whites for kidney transplants.⁵²² In addition, a 1990 report stated that white dialysis patients had a 78 percent higher chance of receiving a cadaveric transplant than black dialysis patients.⁵²³ Eight years later the situation has not significantly improved: black patients remain less likely than other minorities or whites to receive a kidney transplant.⁵²⁴ A complex combination of factors is responsible for the unequal access to kidney transplantation for blacks, including a shortage of kidneys available for transplant,⁵²⁵ a greater need for kidneys by the black population, applicant suitability evaluation procedures that allow wide discretion by physicians, and a govern-

⁵²¹ Office of Inspector General, *The Distribution of Organs for Transplantation: Expectations and Practices* (1991), p. 8; see also Ian Ayres, Laura G. Dooley, and Robert S. Gaston, "Unequal Racial Access to Kidney Transplantation," *Vanderbilt Law Review*, vol. 46 (May 1993), p. 808 (hereafter cited as Ayres et al., "Access to Kidney Transplantation") (citing U.S. Renal Data System, 1990 Annual Report). See also USCCR, *The Health Care Challenge*, vol. I, chap. 3.

⁵²² Office of Inspector General, *The Distribution of Organs for Transplantation: Expectations and Practices* (1991), p. 8.

⁵²³ See Ayres et al., "Access to Kidney Transplantation," p. 808 (citing U.S. Renal Data System, 1990 Annual Report).

⁵²⁴ Laura G. Dooley and Robert S. Gaston, "Stumbling Toward Equity: The Role of Government in Kidney Transplantation," *University of Illinois Law Review*, 1998, p. 715 (hereafter cited as Dooley and Gaston, "Government in Kidney Transplantation.")

⁵²⁵ The efficiency and effectiveness of organ transplantation technology has improved steadily over the past two decades. See Fred H. Cate, "Human Organ Transplantation: The Role of Law," *Iowa Journal of Corporate Law*, vol. 20 (fall 1994), p. 69 (hereafter cited as Cate, "Organ Transplantation: The Role of Law.") The risks associated with organ transplantation have decreased substantially, and the procedure has become relatively common. Douglass, "Organ Donation," p. 201. The advanced state of the technology is reflected both in increased survival rates and in improved quality of life. See Cate, "Organ Transplantation: The Role of Law," p. 69. Unfortunately, however, the number of donors has not increased at a rate that is commensurate with the increased demand for performing the procedure. See General Accounting Office, *Report to Congressional Committees: Organ Transplantation*, GAO/HRD 939-56 (April 1993), p. 12. See also Douglass, "Organ Donation," p. 202. As a result of the shortage of organs, the number of patients who die while waiting for transplants or who remain dependent on less effective therapies grossly outweighs the number of transplants performed. See Cate, "Organ Transplantation: The Role of Law," p. 70.

⁵¹⁷ Ibid.

⁵¹⁸ The guidelines would describe how the investigator would handle the case. The investigator would collect statistical data first, to determine whether such rejections may have caused disparate beneficiary service patterns in that physician's sector of the MCO's service area. If so, the investigator would interview the parties involved to identify the articulated basis of the discrimination, which in this case would be cost savings. The investigator would then apply the legitimate objectives test, by performing a budgetary analysis of the MCO. The analysis would determine to what extent discrimination based upon utilization patterns actually saved costs. The investigator would also seek alternative means of achieving the same level of cost-savings, and negotiate with the MCO to implement these procedures.

⁵¹⁹ The source of a cadaveric organ is a deceased person whose organs were donated.

⁵²⁰ See Lisa Douglass, comment, "Organ Donation, Procurement and Transplantation: The Process, the Problems, the Law," *University of Missouri Kansas Law Review*, vol. 65 (winter 1996), pp. 201-02.

ment-funded allocation system that relies heavily on genetic "antigen matching."⁵²⁶

Although blacks suffer from the shortage of organs in general, the waiting list for kidneys is particularly long⁵²⁷ and is growing longer. The HHS Office of Inspector General (OIG) has taken note of the increasing disparity in recipient waiting time for organ transplants. In a June 1998 report, OIG summarized data showing that in 1988 black recipients waited an average of 20 months for a kidney transplant, while white recipients waited only an average of 11 months. In 1994 the median waiting time for blacks was 40 months, compared with 20 months for whites.⁵²⁸

The need for kidneys among blacks is also greater than that among whites, because blacks experience a higher incidence of renal failure.⁵²⁹ This condition may be associated with socioeconomic factors such as poverty, stress, alcohol use, and poor medical care.⁵³⁰ Another possible explanation that has been advanced is that kidney failure is one of the genetic results of malnutrition endured by slaves.⁵³¹ Whatever the cause, this predisposition to renal failure puts blacks at

⁵²⁶ See generally Dooley and Gaston, "Government in Kidney Transplantation." Antigens are proteins on the surface of kidneys that trigger the body's immune response. Ayres et al., "Access to Kidney Transplantation," p. 807, n. 9. For further explanation of the role of antigens in kidney transplantation, see *ibid.*

⁵²⁷ See Cate, "Organ Transplantation: The Role of Law," p. 70.

⁵²⁸ HHS, Office of Inspector General, *Racial and Geographic Disparity in the Distribution of Organs for Transplantation*, OEI-01-98-000360 (June 1998), p. 2 (hereafter cited as OIG Disparity in Organ Transplantation). The OIG noted that the waiting times for liver transplants are more nearly equal for blacks and whites. *Ibid.*, pp. 2-3. *But see* Lloyd R. Cohen and Melisa Michelsen, "The Efficiency/Equity Puzzle and the Race Issue in Kidney Allocation: A Reply to Ayres, et al., and UNOS," *Annual Review of Law and Ethics*, vol. 4 (1996), p. 148 (citing Donald E. Butkus, et al., "Racial Differences in the Survival of Cadaveric Renal Allografts," *New England Journal of Medicine*, vol. 327 (1992), pp. 840-41 (revealing that waiting times for blacks and whites did not differ when calculated using hemodialysis as a starting point)).

⁵²⁹ See Dooley and Gaston, "Government in Kidney Transplantation," pp. 713-14.

⁵³⁰ Ayres et al., "Access to Kidney Transplantation," p. 842.

⁵³¹ Kathy A. Fackelmann, "The African Gene?" *Science News*, vol. 140 (1991), p. 254. The mutation may have resulted from the adaptation of slaves' bodies to salt deficiency. *Ibid.* See also Ayres et al., "Access to Kidney Transplantation," p. 842, n. 173.

an even more significant disadvantage in their competition for scarce kidneys.

Exacerbating the problems of kidney shortage and a greater need for kidneys among blacks, is the amount of discretion afforded to transplant center physicians who evaluate whether applicants for kidneys are suitable for the transplantation procedure.⁵³² The physician looks at the overall physical, mental, and social resources of the patient.⁵³³ These factors interact in complex ways, some of which may be beyond the capacity of a physician to properly analyze. Further, these factors cannot be analyzed with scientific rigor. In short, this process appears largely arbitrary and unchecked, which raises the specter of racial discrimination in the acceptance of applicants for transplantation.

The factor that has perhaps most affected blacks' access to kidney transplantation is a process called antigen matching.⁵³⁴ Antigen matching is an integral component of the Federal Government-funded system for kidney allocation.⁵³⁵ Because of the financial and organizational structure of the allocation system, it is subject to the nondiscrimination mandate of title VI.⁵³⁶ Thus, the disparate effects of antigen matching may be vulnerable to attack under that provision.

Federal Organ Allocation Policy

The Federal Government has taken several important steps to address the issue of equity in organ transplantation. Shortly after the procedure became a practicable method of treating patients with organ failure, the Federal Government began to shoulder some of the responsibility for achieving equity in the transplant arena. With regard to kidney transplantation, Congress attempted to ensure that this technology would be widely available to Americans in 1972 when it authorized medicare funding for virtually all kidney transplants.⁵³⁷ Congress took

⁵³² See Dooley and Gaston, "Government in Kidney Transplantation," pp. 715-16.

⁵³³ *Ibid.*

⁵³⁴ *Ibid.*, pp. 704-05.

⁵³⁵ See UNOS Policies, accessed at <http://www.unos.org/About/policy_h.htm> (hereafter cited as UNOS Policies).

⁵³⁶ See 42 U.S.C. §§ 2000d to 2000d-7 (1994).

⁵³⁷ See Social Security Amendments Act of 1972, Pub. L. No. 92-603, § 299I, 86 Stat. 1329, 1463-64 (codified at 42 U.S.C.

further steps to make organ allocation equitable in 1984 when it passed the National Organ Transplant Act.⁵³⁸ This statute authorized creation of the Organ Procurement and Transplantation Network (OPTN), which was charged with establishing a national waiting list for organs, a procedure for matching available organs with registered individuals, and a system for allocating organs.⁵³⁹ The Secretary of HHS has promulgated regulations governing the operations of the OPTN, including how it must establish organ allocation policies.⁵⁴⁰ The agency that serves as the OPTN is a private, nonprofit organization called the United Network for Organ Sharing (UNOS).⁵⁴¹ In 1986 Congress conditioned all Medicare and Medicaid reimbursement to hospitals on compliance with OPTN policies, effectively making such compliance mandatory.⁵⁴²

UNOS has developed procedures for allocating organs among registered applicants.⁵⁴³ The organization designed a system for the allocation of kidneys that assigns points, primarily based on the extent to which an applicant's kidney matches a prospective donor's kidney.⁵⁴⁴ Other factors are the medical likelihood of the appli-

cant finding a matching kidney in the future, the length of time on the waiting list, and age.⁵⁴⁵ Although the UNOS system attempts to allocate kidneys equitably based on medical probability of nonrejection,⁵⁴⁶ the system has inadvertently curtailed blacks' access to kidneys. One of the main forces behind this effect is a UNOS policy that relies heavily on antigen matching in the applicant screening process.⁵⁴⁷

In determining the degree of a match, the unit of measure is the antigen, a protein on the surface of tissues that allows the immune system to identify foreign tissues.⁵⁴⁸ Without immuno-suppression drug therapy, the immune system will attack tissue that it recognizes as foreign.⁵⁴⁹ Thus, if a transplanted kidney or other organ contains antigens that the immune system perceives as foreign, the organ has a greater chance of being rejected. If, however, all antigens on the donor's organ match those on the recipient's, the organ has the greatest probability of being accepted by the recipient's body.⁵⁵⁰ Generally, a transplant applicant for whom all antigens match, then, represents the best probability of nonrejection, and is called a "zero-antigen mismatched patient."⁵⁵¹

To reduce the possibility of rejection, UNOS policy requires that the antigens of each donated kidney be compared with those of all applicant kidneys nationwide.⁵⁵² One of two basic approaches to allocation is used depending on whether a donated kidney exhibits a zero-antigen mismatch with any of the applicants'

§ 426 (1994)). See also Dooley and Gaston, "Government in Kidney Transplantation," p. 718.

⁵³⁸ Pub. L. No. 98-507, 98 Stat. 2339 (codified as amended in scattered sections of 42 U.S.C.).

⁵³⁹ See 42 U.S.C. § 274 (1994). The statute also directed the establishment of "organ procurement organizations," (OPOs) which are also members of the OPTN. *Id.*, 42 U.S.C. § 273 (a) (1994). These organizations receive HHS funds to coordinate organ procurement and allocation in localized geographic areas. *Id.* As recipients of HHS funds, OPOs are also obligated by the nondiscrimination provisions of title VI.

⁵⁴⁰ See 63 Fed. Reg. 16296, 16332 (1998) (to be codified at 42 C.F.R. pt. 121). The regulation was developed by the Health Resources and Services Administration (HRSA) with assistance from other agencies, including OCR staff. Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 3.

⁵⁴¹ The statute mandates that the organization be a private nonprofit entity. 42 U.S.C. § 274(b)(1)(A)(1994). See also Dooley and Gaston, "Government in Kidney Transplantation," p. 709; Ayres et al., "Access to Kidney Transplantation," p. 813.

⁵⁴² See the Sixth Omnibus Budget Reconciliation Act (SOBRA), Pub. L. No. 99-509, § 9318 (a), 100 Stat. 2009-10 (1986) (codified at 42 U.S.C. § 1320b-8 (1994)).

⁵⁴³ See generally UNOS Policies.

⁵⁴⁴ See generally *ibid.*; Dooley and Gaston, "Government in Kidney Transplantation," p. 703, n. 4; Ayres et al., "Access to Kidney Transplantation," p. 818.

⁵⁴⁵ See UNOS Policies, No. 3.5.9; Ayres et al., "Access to Kidney Transplantation," p. 819 and n. 61.

⁵⁴⁶ The point system awards the most points for patients with zero-antigen mismatches, and for patients who exhibit a small likelihood of matching future donor kidneys, as compared with the length of time on the waiting list and age. UNOS Policies, No. 3.5.9.

⁵⁴⁷ See Dooley and Gaston, "Government in Kidney Transplantation," pp. 704-05; Ayres et al., "Access to Kidney Transplantation," pp. 808-09.

⁵⁴⁸ Dooley and Gaston, "Government in Kidney Transplantation," p. 703, n. 4; Ayres et al., "Access to Kidney Transplantation," p. 808, n. 9; p. 815.

⁵⁴⁹ Ayres et al., "Access to Kidney Transplantation," p. 808, n. 9.

⁵⁵⁰ *Ibid.*, pp. 815-16. Generally, there are six antigens on each kidney. *Ibid.*

⁵⁵¹ See UNOS Policies, No. 3.5.2.1, defining "zero antigen mismatch."

⁵⁵² See UNOS Policies, No. 3.5.2.2.

kidneys. If a zero-antigen mismatched patient exists, that patient must receive the kidney, regardless of where that patient lives.⁵⁵³ If there is more than one zero-antigen mismatched patient, UNOS policy directs the relevant health professionals to award the kidney based on a complex set of criteria that includes the geographic location of each of the applicants, the likelihood of each applicant obtaining a matching kidney in the future, each applicant's time spent on the waiting list, and other genetic factors.⁵⁵⁴ When the donor kidney cannot be matched according to the zero-antigen mismatch standard, the point system is used to find the best "partial antigen match."⁵⁵⁵ For example, a patient whose kidney had two antigens that matched the potential donor kidney would receive more points, holding other factors constant, than a patient whose kidney held only one matching antigen.

The UNOS policies that govern the allocation of kidneys based on matching antigens affect black applicants disproportionately. Most donated kidneys originate from white donors, and those kidneys tend to have different antigens than kidneys that belong to blacks.⁵⁵⁶ The greatest impact on blacks occurs where partial matching is necessary because these cases happen more frequently. In 1993 two commentators estimated that, under the then-proposed zero-antigen mismatch test,⁵⁵⁷ only 25 percent of cadaveric donations would be paired with applicant kidneys as zero-antigen mismatches.⁵⁵⁸ If those projections were correct, approximately 75 percent of today's donated kidneys must be partially matched.

Using Title VI to Effect Equal Access

If UNOS policies cause blacks to receive kidneys (or other organs) at disproportionately low

rates, these policies violate title VI.⁵⁵⁹ UNOS is a private entity that receives Federal program funds through its contract with HHS, and so are the organ procurement organizations that coordinate kidney transplants at the local level.⁵⁶⁰ Thus, UNOS, as a recipient under title VI, is prohibited from implementing policies that disparately affect minorities without a legitimate medical justification.⁵⁶¹ Hence, applying OCR's own legitimate objective test (identified in a 1981 policy memorandum) the antigen-matching policy, which prevents a disproportionate number of black patients from obtaining kidneys, must be necessary to further a legitimate objective of the recipient.⁵⁶² One objective of the UNOS policies is to ensure that organs (here, kidneys) are distributed fairly and effectively, a legitimate objective.⁵⁶³ Yet whether the antigen-matching policy is necessary to further this objective is less obvious.⁵⁶⁴ Research has shown that zero-antigen mismatches increase the chance of a body's kidney acceptance by 10 percent,⁵⁶⁵ thus, the process for *full* antigen matching might potentially pass OCR's legitimate objective test.

By contrast, however, the necessity of the *partial* antigen-matching process is currently under debate.⁵⁶⁶ According to some commenta-

⁵⁵³ UNOS Policies, No. 3.5.2.3.1.

⁵⁵⁴ *Ibid.*

⁵⁵⁵ UNOS Policies, No. 3.5.5. A partial antigen match evaluates the number of antigens that match between the donor kidney and a patient that is not a zero-antigen mismatched patient. See Dooley and Gaston, "Government in Kidney Transplantation," p. 720.

⁵⁵⁶ Ayres et al., "Access to Kidney Transplantation," p. 823.

⁵⁵⁷ UNOS was considering migrating from the "six-antigen match" test to the zero-antigen mismatch test in 1993. See Dooley and Gaston, "Government in Kidney Transplantation," p. 817.

⁵⁵⁸ Ayres et al., "Access to Kidney Transplantation," p. 817.

⁵⁵⁹ *Ibid.*, pp. 853-60.

⁵⁶⁰ See 42 U.S.C. §§ 273(a), 274(a)-(b) (1994).

⁵⁶¹ For a discussion of this test, and other standards used to assess a recipient's justification for its discriminatory policies or practices, see "Defining Prohibited Discriminatory Practices," above. See also Chavkin letter, p. 2. See also Ayres et al., "Access to Kidney Transplantation," pp. 856-57.

⁵⁶² *Ibid.*

⁵⁶³ See 42 U.S.C. § 273(b)(1)(E) (1994).

⁵⁶⁴ In fact, the change in UNOS Policies 3.5.6.1 and 3.5.6.2 between 1994 and 1995 illustrates UNOS' acknowledgment of the disparities in kidney allocation between blacks and whites. Compare UNOS Policies 3.5.6.1 and 3.5.6.2 (1994) with UNOS Policies 3.5.6.1 and 3.5.6.2 (1995) (reducing the number of points afforded perfect antigen matches from 10 to 7, and increasing the number of points afforded for length of time on the waiting list).

⁵⁶⁵ S. Takemoto, E. Carnahan, and P.I. Terasaki, "A Report of 504 Six Antigen-Matched Transplants," *Transplantation Proc.*, vol. 23 (1991), p. 1318. See also Ayres et al., "Access to Kidney Transplantation," p. 829, n. 112.

⁵⁶⁶ Compare Ayres et al., "Access to Kidney Transplantation," pp. 830-33 (citing several studies of black transplant recipients as evidence that partial antigen matching does not benefit blacks) (citations omitted) with Cohen and Michelsen, "The Efficiency/Equity Puzzle," pp. 154-55 and

tors, partial antigen matching has not been shown to substantially increase transplant success.⁵⁶⁷ Moreover, there appear to be less discriminatory alternative means for distributing organs fairly and effectively. For example, commentators in opposition to partial antigen matching cite immuno-suppression drug therapy as a proven-effective treatment, even for kidneys that exhibit only a partial antigen match.⁵⁶⁸ These commentators assert that when drugs such as cyclosporine are used, partial antigen matching becomes unnecessary.⁵⁶⁹ In view of the assertions of these commentators, it appears that partial antigen matching creates a disparate impact on blacks that is not necessary to further the legitimate objective of distributing kidneys fairly and effectively.

OCR's Role as Title VI Enforcer in Organ Transplantation

As the agency charged with ensuring that recipients of HHS funds comply with the title VI nondiscrimination mandate, OCR has responsibility to vigorously enforce title VI with regard to UNOS, just as it must with all other recipients.⁵⁷⁰ OCR must review the policies and procedures of UNOS for potential discriminatory effects, and conduct technical assistance to prevent and resolve violations. In the case of UNOS, a limited-scope compliance review would be sufficient to find a potential violation, because, according to some commentators, data already exist suggesting the potential disparate effects of UNOS allocation policies.⁵⁷¹ OCR should consult with outside medical experts to determine whether the disparate effects are medically justified. In order to eliminate the adverse effects,

OCR should provide technical assistance to UNOS in the form of assisting that agency in reevaluating the point system for kidney allocation, as well as procedures in place for the allocation of other organs. Medical experts, policy analysts, and advocacy groups should be invited to join in the entire investigative process. The agency should also develop a policy guidance for UNOS, organ procurement organizations (OPOs), and transplant centers so that they are aware of the nondiscrimination mandate in the acceptance of applicants for organ transplantation. Such guidance should make clear that race should not be a factor in suitability evaluations, other than to the extent it is relevant for medical purposes.

Minority Recruitment to Medical Schools

*"Increasing the proportion of racial and ethnic minorities in medicine and dentistry has been shown to be an effective way to improve health care for the underserved."*⁵⁷²

OCR has not addressed in policy guidance medical school admissions policies and their implications for achieving equal access to quality health care for minorities. As of July 1999, OCR had not developed any guidance on nondiscrimination in this context. A potentially effective vehicle for addressing this issue is OCR's title VI regulatory guidance permitting affirmative action policies to remedy past discrimination and to "overcome the effects of conditions which resulted in limiting participation by persons of a particular race, color or national origin."⁵⁷³

nn. 84-89 (citing four studies as support for the medical benefits of partial antigen matching) (citations omitted).

⁵⁶⁷ Ayres et al., "Access to Kidney Transplantation," pp. 830-33.

⁵⁶⁸ Ibid., pp. 833-35.

⁵⁶⁹ Ibid., pp. 856-57.

⁵⁷⁰ See U.S. Attorney General Janet Reno, U.S. Department of Justice, memorandum for Heads of Departments and Agencies that Provide Federal Financial Assistance, July 14, 1994 (re: use of the disparate impact standard in administrative regulations under title VI of the Civil Rights Act of 1964) (urging vigorous enforcement by agencies with title VI responsibility).

⁵⁷¹ See Ayres et al., "Access to Kidney Transplantation," pp. 830-33 (discussing the scientific data that suggest partial antigen matching does not significantly increase chances for nonrejection.)

⁵⁷² Nebraska Office of Minority Health, Nebraska Department of Health, "The Color of Health: A Vision for Change, 1996 Nebraska Minority Health Conference Report, Oct. 15-16, 1996, p. 27 (hereafter cited as NE Dept. of Health, "The Color of Health").

⁵⁷³ 45 C.F.R. § 80.3(b)(6)(i)-(ii) (1998). The Commission's definition of "affirmative action" has been published most recently in a July 1995 briefing paper. It states:

Affirmative action is a contemporary term that encompasses any measure, beyond simple termination of a discriminatory practice, that permits the consideration of race, national origin, sex, or disability, along with other criteria, and which is adopted to provide opportunities to a class of qualified individuals who have either historically or actually been denied those opportunities and/or prevent the recurrence of discrimination in the future.

USCCR, Office of General Counsel, "Briefing Paper for the U.S. Commission on Civil Rights Legislative, Executive, and Judicial Development of Affirmative Action," July 1995. See

The use of affirmative action policies has been significantly curtailed by the Federal courts during the 1990s.⁵⁷⁴ Although the Supreme Court has sanctioned the use of race-conscious measures to eliminate discrimination,⁵⁷⁵ in the last decade the Federal courts have created an ever-narrower ambit of permissible affirmative action policies while displaying an ever-increasing hostility to their continued presence.⁵⁷⁶ The persistent yet baffling denial of the social, economic, and historical realities depriving our medical profession of minority physicians is reflected in these recent interpretations of the law. It appears, based on recent Supreme Court decisions, that almost all efforts to meet the need for minority professionals to gain access to the many fields traditionally closed to them, particularly law, medicine, and business, are impermissible under the Constitution. It seems that almost all efforts by Federal, State, and local governments to meet this need cannot, to use the legal jargon of the Court, meet its "strict scrutiny" standard.

For example, in *Adarand Constructors, Inc. v. Peña*,⁵⁷⁷ the Court tested the constitutionality of a Department of Transportation contracting program requiring that "not less than 5 percent of the total value of all prime contract and sub-contract awards for each fiscal year" would go to businesses operated by members of "socially and

economically disadvantaged" groups, where the term "socially and economically" required a *presumption* of including blacks, Hispanics, Native Americans, Asian Americans, Pacific Islanders, and "other minorities or any other individual found to be disadvantaged by the [Small Business] Administration pursuant to section 8(a) of the Small Business Act."⁵⁷⁸ The importance of *Adarand* was the Supreme Court's holding that all racial classifications, whether part of a Federal, State, or local government plan, must be scrutinized under a "strict scrutiny" standard.⁵⁷⁹ Applying this standard, government action of any kind is only constitutionally permissible if the government can show that it had a "compelling" reason for the plan and that the plan was "narrowly tailored" to meet that objective.⁵⁸⁰ This is the Court's most searching form of scrutiny, and government action subjected to it will have great difficulty surviving a constitutional challenge. Moreover, the Court has indicated that the goal of redressing societal discrimination is not a sufficiently "compelling" interest to undertake a race-conscious remedial plan.⁵⁸¹

also USCCR, *Statement on Affirmative Action*, clearinghouse pub. 54 (October 1977); USCCR, *Affirmative Action in the 1980s: Dismantling the Process of Discrimination*, November 1981.

⁵⁷⁴ See, e.g., *Adarand Constructors, Inc. v. Peña*, 515 U.S. 200, 115 S. Ct. 2097, 132 L. Ed. 2d 158 (1995); *City of Richmond v. J.A. Croson Co.*, 488 U.S. 469 (1989).

⁵⁷⁵ See, e.g., *United States v. Fordice*, 505 U.S. 717, 120 L. Ed. 2d 575, 112 S. Ct. 2727 (1992); *United States v. Paradise*, 480 U.S. 149, 167 (1987); *Swann v. Charlotte-Mecklenberg Board of Education*, 402 U.S. 1, 15-16 (1971); *McDaniel v. Barresi*, 402 U.S. 39 (1971); *Green v. County School Board of New Kent County*, 391 U.S. 430, 438 (1968).

⁵⁷⁶ See, e.g., *Adarand*, 515 U.S. 200 (1995); *Croson*, 488 U.S. 469 (1989). In *Croson*, the Supreme Court invalidated a program that required prime contractors who were awarded city construction contracts to subcontract 30 percent of their contracts to minority-owned business. 488 U.S. at 477-86. The Court held that State and local government affirmative action policies are tested against the court's most stringent standard, "strict scrutiny." Six years later in *Adarand*, the court extended the "strict scrutiny" to include Federal action as well. 515 U.S. 200, 227).

⁵⁷⁷ 515 U.S. 200, 115 S. Ct. 2097, 132 L. Ed. 2d 158 (1995).

⁵⁷⁸ 515 U.S. at 205 (citing the Small Business Act, 15 U.S.C. § 637(d)(C)(3) (1994)). This provision of the Small Business Act states "the contractor shall presume that socially and economically disadvantaged individuals include Black Americans, Hispanic Americans, Native Americans, Asian Pacific Americans, and other minorities, or any other individual found to be disadvantaged by the [Small Business] Administration pursuant to section 8(a) of the Small Business Act." *Id.*

⁵⁷⁹ 515 U.S. at 227 (stating: "[W]e hold today that all racial classifications, imposed by whatever federal, state, or local governmental actor, must be analyzed by a reviewing court under strict scrutiny. In other words, such classifications are constitutional only if they are narrowly tailored measures that further compelling governmental interests."). The Court vacated the Tenth Circuit's decision and remanded the case for review of the DOT program under the "strict scrutiny" standard. 515 U.S. at 239. See 16 F.3d 1537, 1547 (10th Cir. 1994) for the tenth circuit's decision upholding the constitutionality of the DOT program's use of subcontractor compensation clauses.

⁵⁸⁰ 515 U.S. 200, 235-237. See also *City of Richmond v. J.A. Croson Co.*, 488 U.S. 469, 493-494 (1989) (applying the strict scrutiny standard to minority set-aside plans); *Wygant v. Jackson Bd. of Educ.*, 476 U.S. 267, 277-78, 90 L. Ed. 2d 260, 106 S. Ct. 1842 (1986) (plurality opinion) (applying the strict scrutiny standard in the education context).

⁵⁸¹ 488 U.S. 469, 498-501 (stating that "an amorphous claim that there has been past discrimination in a particular industry cannot justify the use of an unyielding racial quota." *Id.* at 499.)

Nonetheless, even in *Adarand*, a case whose name has become synonymous with anti-affirmative action sentiment, the Court left the door open for *some* kinds of affirmative action plans. The Court acknowledged:

[W]e wish to dispel the notion that strict scrutiny is "strict in theory, but fatal in fact." . . . The unhappy persistence of both the practice and the lingering effects of racial discrimination against minority groups in this country is an unfortunate reality, and government is not disqualified from acting in response to it When race-based action is necessary to further a compelling interest, such action is within constitutional constraints if it satisfies the "narrow tailoring" test this Court has set out in previous cases.⁵⁸²

Moreover, regardless of the perspectives presented in certain judicial interpretations of a particular time period and political bent, there is a moral imperative of a more permanent nature, an obligation, to ensure equality of opportunity in education for the economically underprivileged, many of whom happen to be members of racial/ethnic minority groups. As one educator has observed: "We cannot have excellent universities if they do not mirror the diversity in our society."⁵⁸³ There can be no diversity in the medical profession until we as a Nation fully recognize what our "compelling interests" truly are.

OCR has an important role to play in efforts to ensure more minority physicians in the future. It is especially important for OCR to develop some form of policy guidance for medical schools to address this issue. Of all programs assisted by HHS funds, medical schools are certainly one of the most crucial from a civil rights perspective.

Role of Minority Physicians in Providing Equal Access to Quality Care

Ensuring nondiscrimination in medical school admissions and medical studies can play a major role in expanding equal access for minority medical students and, ultimately, for health care services to minorities. Data presented by numerous government reports, private commentators, and researchers demonstrate the success of

diversity programs at universities and graduate and professional schools.⁵⁸⁴ These reports should provide the basis for an introductory section of an OCR policy guidance on medical school admissions. This discussion should set forth as much data and commentary as possible on the need for title VI compliance among medical schools by illustrating that racial/ethnic disparities continue in the medical professions, and the negative effect these disparities have on minorities' access to quality health care.

Just a few examples of the data and commentary addressing minority access to medical practice illustrate the importance of ensuring that medical schools do not discriminate on the basis of race, color, or national origin. For instance, HHS data have shown that minority physicians are more likely than their white counterparts to serve minority patients; black physicians are five times more likely than their white counterparts to treat black patients; and Hispanic physicians are 2.5 times more likely to treat Hispanic patients than are other doctors.⁵⁸⁵

Similarly, a review of literature addressing barriers faced by minorities and women in gaining access to and performing successfully in medical school reveals significant concerns among commentators. For example, one editorialist writing in a letter to the *Journal of American Medical Women's Association* noted:

[T]he rationale for a racially diverse physician workforce is robust, going beyond equity to include the now well-documented disproportionate role that minority physicians play in serving poor and minority patients;

⁵⁸⁴ See HHS, Health Resources and Services Administration, *Health Care Rx: Access for All*, the President's Initiative on Race, 1998 (hereafter cited as HRSA, *Health Care Rx*); Miriam Komaromy et al, "The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations," *New England Journal of Medicine*, vol. 334 (May 16, 1996), pp. 1305-10; Herbert W. Nickens, "The Rationale for Minority-Targeted Programs in Medicine in the 1990s," *Journal of the American Medical Association*, vol. 267, no. 17 (May 6, 1992), p. 2390; Eliseo J. Perez-Stable, Anna Napoles-Springer, and Jose M. Miramontes, "The Effects of Ethnicity and Language on Medical Outcomes of Patients with Hypertension or Diabetes," *Medical Care*, vol. 35, no. 12 (1997), p. 1212; Donald L. Libby, Zijun Zhou, and David Kindig, "Will Minority Physician Supply Meet U.S. Needs? Projections for Reaching Racial Parity of Physicians to Population," *Health Affairs*, July-August 1997. See also USCCR, *The Health Care Challenge*, vol. I, chap. 2, for a full discussion on minority health care professionals.

⁵⁸⁵ HRSA, *Health Care Rx*, p. 12.

⁵⁸² 515 U.S. at 237 (citations omitted).

⁵⁸³ L. Lee Knefelkamp, professor, University of Michigan, made during a public lecture in Ann Arbor, Feb. 9, 1998.

and the necessity of diversity among students and faculty to produce physicians who can deliver culturally competent health care to our increasingly diverse populations.⁵⁸⁶

Further, the Nebraska Office of Minority Health has reported that minority physicians often practice in racially/ethnically underserved areas and are more likely to practice primary care than white doctors, thus the “[a]vailability of racial/ethnic minority providers tends to eliminate some of the language and cultural barriers that limit access to care.”⁵⁸⁷

The American Association of Medical Colleges has stated that relying only on grade point averages and test scores in medical school admissions decisions, ignores “patients’ demand for physicians who can help them stay healthy and effectively and systematically treat them when they are ill.”⁵⁸⁸ The association continued:

Affirmative action combined with other educational enrichment programs are vital to increase the nation’s small but important supply of minority physicians. Loss of these programs would result in even more Americans without access to key health care services, needless individual suffering, and a worsening health status for the nation The medical profession cannot let attacks on affirmative action lessen its commitment to serving all segments of society. This nation urgently needs more physicians who are ready and willing to serve the inner cities and rural townships, as well as physicians who understand the unique challenges of providing care in medically underserved communities.⁵⁸⁹

The University of Michigan, recently brought together a team of leading scholars to show that there is a compelling need for racial, ethnic, and cultural diversity in higher education. According to the university, its empirical analysis showing the benefits of this kind of diversity indicates that “patterns of racial segregation and separation historically rooted in our national life can be broken down by diversity experiences in higher

education.”⁵⁹⁰ The university’s findings suggest that higher education programs seeking such diversity may be breaking down barriers to integration, nondiscrimination, and equality of opportunity in all facets of life experience, including access to health care.

Recognizing the vital role minority physicians play in the delivery of health services to economically disadvantaged and minority populations, many medical schools are attempting to increase the enrollment of minority medical students. Many of the institutional initiatives are innovative and effective, and at the same time are relatively simple in design and implementation, which make them excellent models to be replicated by other programs.

Two of the areas that require reassessment, if the attempts at increased inclusion of minority students are to be successful, are the availability of financial assistance and recruitment and admissions procedures. It is important to note the distinction between initiatives undertaken to increase minority representation in medical schools and other diversity programs. These programs do not guarantee admission based on minority status, but rather seek to increase the number of minority applicants, thereby increasing the pool of available minority students and at the same time maintaining the admission standards for all students.

In regard to increasing minority enrollment in medical schools, one university medical center noted:

The goal of greatly increased enrollment of underrepresented minorities in medical school in America today is a moral, social, and corporate imperative calling for bold and demanding efforts which, to use an analog from the practice of medicine itself, might justly be described as “heroic.”

Reduced to its simplest components, the problem presents as the accelerating growth of a major segment of our society that has steadily outpaced the development of resources to meet its most basic health needs. Identified as a high priority of the Association of American Medical Colleges (AAMC) a generation ago, the problem appeared at first to be responding to early energetic efforts to bring minority physicians and populations into better balance. The

⁵⁸⁶ Kim Fielder, M.S., University of California, Berkeley–San Francisco, letter to the Editor, *Journal of the American Medical Women’s Association*, vol. 51, no. 4 (August/October 1996), p. 171.

⁵⁸⁷ NE Dept. of Health, “The Color of Health,” p. 27.

⁵⁸⁸ American Association of Medical Colleges, “Affirmative Action in Medicine,” p. 2 (July 1996) (hereafter AAMC, “Affirmative Action in Medicine”).

⁵⁸⁹ AAMC, “Affirmative Action in Medicine,” p. 4.

⁵⁹⁰ The University of Michigan, *The Compelling Need for Diversity*, accessed at <<http://www.umich.edu/~newsinfo/Admission/Expert/toc.html>>.

worsening condition of an expanding low-income population in the 1980s, however, together with a loss of momentum in medical recruitment efforts due to competing forces in our society, has lent added urgency to the need to reverse the impact of these trends.⁵⁹¹

Rush University in Chicago has implemented several student diversity initiatives targeting a broad range of areas in which recruitment efforts are crucial. In the early 1990s, the medical and nursing colleges at Rush established a task force in each college that produced a series of recommendations.⁵⁹² Many of the recommendations required little additional funding, but rather relied on modification of existing programs. Among the positive results have been a significant improvement in minority student recruitment, retention, and graduation, and the creation of a position for minority affairs in each college. Rush completed these programs with little assistance from Federal funds, relying mainly on institutional resources and foundation funding. As of March 1999, in the medical college, 10.5 percent of the 487 students were from underrepresented minority groups, 23.6 percent were Asian American, and 46 percent were women.⁵⁹³

Active recruitment of minority students into medical careers not only requires an ample pool of minority applicants, but also requires that minority students be given opportunities to pursue these careers early in their education. In an attempt to influence students at a young age, the Rush-Presbyterian-St. Luke's Medical Center has developed a program in conjunction with several private organizations called the Science and Math Excellence (SAME) Network, which is designed to improve the math and science skills of students in the Chicago school system, par-

ticularly in inner-city communities.⁵⁹⁴ Tactics of the SAME Network include the building of science labs in schools that had none and a mobile science lab (a transformed Rush bloodmobile) that travels to area elementary schools giving students hands-on experience. In collaboration with Chicago public schools, Rush also provides 40 high school students who show an interest in math and science a year-round internship opportunity at the medical center.⁵⁹⁵

In an attempt to recruit students at the junior and senior levels of college, Rush also sponsors a total immersion Summer Prep Program in which minority students participate in a comprehensive 8-week course of activities aimed at making them better applicants to medical school.⁵⁹⁶ The program focuses on self-motivation, study skills, an introduction to medical school subjects, and preparation for the MCAT and the medical school application and interview process.⁵⁹⁷

Native Americans are the most severely underrepresented minority group in medical professions.⁵⁹⁸ To address this concern, the University of Utah School of Medicine has established the Utah Indian Nations Science Outreach Program in an effort to develop interest in science among elementary, junior high, and high school students in schools on or near Indian reservations in the State.⁵⁹⁹ Staff, faculty, and medical students give presentations on scientific topics that parallel the schools' curricula and apply scientific principles to aspects of medicine. Students engage in hands-on activities and are encouraged to interact with presenters.⁶⁰⁰

The Women's Health Program and several other departments in the University of Michigan Health System participate in mentoring and experiential learning opportunities for minority

⁵⁹¹ Rush-Presbyterian-St. Luke's Medical Center/Rush University, *Rush Equal Access to Careers in Health*, The Report of the Rush Task Force on the Recruitment of Minority Medical Students, adopted June 26, 1991, p. 1 (hereafter cited as Rush University, *Equal Access to Careers in Health*).

⁵⁹² Leo M. Henikoff, president of Rush-Presbyterian-St. Luke's Medical Center, Rush University and the Rush System for Health, Chicago, IL, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 19, 1999 (re: information for health care project), enclosure, p. 4 (hereafter cited as Henikoff letter).

⁵⁹³ *Ibid.*, letter, p. 4.

⁵⁹⁴ *Ibid.*, enclosure, "The Science and Math Excellence Network."

⁵⁹⁵ *Ibid.*

⁵⁹⁶ Rush University, *Equal Access to Careers in Health*, p. 20.

⁵⁹⁷ *Ibid.*

⁵⁹⁸ See USCCR, *The Health Care Challenge*, vol. I, chap. 2.

⁵⁹⁹ Jesse M. Soriano, director of Health Sciences, Office of Ethnic Minority Affairs, University of Utah, letter to Mireille Zieseniss, USCCR, May 19, 1999 (re: information for health care project), attachment 5, p. 1 (hereafter cited as Soriano letter).

⁶⁰⁰ Soriano letter, attachment 5, p. 1.

high school and college students. The School of Public Health sponsors a summer enrichment program for minority students who are interested in careers in health and medical fields. Each student participant works with an assigned department as a staff member for the entire summer and participates in other career development and graduate school preparatory courses.⁶⁰¹

The Office of the Dean at the University of Missouri School of Medicine has also initiated activities to increase the number of minority medical students, including the appointment of an assistant dean with the responsibility for minority affairs. The university operates the Missouri High School Summer Program and a university-level companion program called the Premedical Sciences Enrichment Program. The purpose of these programs is to bring students from underrepresented minority groups who are interested in medicine as a career to campus for a 6-week residential program that includes preparation for the MCAT, work with a faculty mentor on a research project, and clinical experience with a role model physician.⁶⁰²

At the Yale School of Medicine diversity efforts have been the focus of the Office of Multicultural Affairs. One program, cosponsored by the National Heart, Lung and Blood Institute, the Biomedical Summer Research Training and Enrichment Program (BioSTEP), allows students to engage in biomedical research in a faculty lab for 10 weeks gaining practical experiences with research techniques. Yale also hosts the Minority Medical Education Program (in conjunction with the AAMC's Project 3000 by 2000) that helps 100 premed students from all over the country by improving their learning skills, preparing them for the MCAT, and introducing them to the rigors of medical school curricula.⁶⁰³

⁶⁰¹ Gilbert S. Omenn, executive vice president for Medical Affairs and CEO, University of Michigan Health System, Ann Arbor, MI, letter to Frederick D. Isler, assistant staff director for civil rights evaluation, USCCR, Mar. 15, 1999 (re: information for health care project), p. 3.

⁶⁰² William A. Altemeier, associate dean for Medical Education, University of Missouri School of Medicine, Columbia, MO, letter to Mireille Zieseniss, USCCR, Apr. 1, 1999 (re: information for health care project), attachment G.

⁶⁰³ Ruth Katz, associate dean for Administration, Yale University School of Medicine, New Haven, CT, letter to Frederick D. Isler, assistant staff director for Civil Rights

At Boston Medical Center (affiliated with Boston University), minority recruitment efforts extend to residency programs. Boston Medical Center began a minority recruitment program in 1980. This is a 1-month subsidized elective program for fourth year medical students from medical schools around the country that seeks to recruit these students following graduation. Of the 14 to 15 minority students who attend the program each month, 4 or 5 remain at Boston Medical Center for their residencies.⁶⁰⁴

The Wake Forest University School of Medicine offers a post-baccalaureate development program to facilitate the entrance of minority and disadvantaged students into medical school. Students entering the 12-month program must already have completed a bachelor's degree. After successful completion of the program (for which tuition is waived) the students are automatically offered admission to the School of Medicine as first year medical students.⁶⁰⁵ In this program not only are students given the opportunity to prepare for medical school, but are given the financial assistance to do so.

To recruit minority medical students and address the needs of rural underserved communities, Texas A&M University Health Science Center has developed the Partnership for Primary Care Program (PPC). The PPC is an early acceptance program that accepts students in the top 10 percent of their high school class who have an interest in medicine and who are interested in working in rural areas or with underserved populations. The students themselves must come from rural communities. (In 1998 the pilot year for the project, nine students were admitted to the program—three whites, three Hispanics, and three Asian Americans).⁶⁰⁶ The students are accepted as undergraduates and can later attend medical school without taking the MCAT, as

Evaluation, USCCR, Mar. 17, 1999 (re: information for health care project), p. 2. See USCCR, *The Health Care Challenge*, vol. I for a discussion of Project 3000 by 2000.

⁶⁰⁴ Boston Medical Center, *Catalog of Diversity Programs*, November 1998.

⁶⁰⁵ Gary Eckenroth, university compliance officer, Wake Forest University, Winston-Salem, NC, letter to Mireille Zieseniss, USCCR, Mar. 15, 1999 (re: information for health care project), enclosure, p. 2.

⁶⁰⁶ Valerie T. Beugen, staff attorney, Texas A & M University System, Office of General Counsel, College Station, TX, letter to Mireille Zieseniss, USCCR, Feb. 26, 1999 (re: information for health care project), p. 2.

long as they have performed satisfactorily in their undergraduate studies. The purpose of the program is to allow students to enter medical school based on factors other than a standardized test, on which historically minority students have not fared as well as whites.⁶⁰⁷ During the medical students' third year of studies, they are required to spend up to 9 months in rural areas focusing on clinical applications.⁶⁰⁸

The task force at Rush also found that minority students are more favorably disposed toward those medical schools that show early and frequent interest and from which they receive earlier acceptances and offers of financial assistance.⁶⁰⁹ The task force recommended an Endowed Scholars Program to provide scholarships in the health science programs, and a Revolving Student Loan Fund that will offer low-interest rates and an extended repayment plan to begin 4 years after graduation, when most students have completed their residencies. Several other medical schools have established similar financial aid programs.⁶¹⁰

Once minority students have been recruited, retention presents an additional challenge. After students are accepted to Rush Medical College, they are given the opportunity to participate in a 4-week program before beginning the academic year, which is designed to introduce them to the medical school, identify any deficiencies individual students may have, and begin improvements. In 1988 a program was created as a vol-

unteer project of minority faculty members. It pairs each participating faculty physician with one student of the same ethnic group and gender, if possible.⁶¹¹ These faculty members serve as an additional source of support for minority medical students.

These are just a few of the many examples of diversity initiatives aimed at increasing minority student interest in medical professions. Access to educational opportunities in the sciences, financial assistance, and early introduction into the field of medicine all play a vital role in the recruitment of underrepresented minority medical students. Schools of medicine have an obligation to increase the enrollment of minorities in order to diversify research agendas, improve patient care, and eventually reduce disparities in health status among minority groups. Unfortunately, some of the programs described above may be in peril due to the Federal courts' recent attack on affirmative action policies.

Evaluating Civil Rights Compliance in Admissions Policies

As the discussion above indicates, medical schools use a variety of creative policies to help ensure minority access to medical study. However, just as there is an academic perspective on how or whether affirmative action policies should be implemented there is a legal perspective as well. Exposure to affirmative action policies from a legal standpoint is necessary for a complete understanding of the issues. However, judges, including the current Supreme Court justices, do not necessarily possess expertise in developing diversity programs. The parameters they have drawn around affirmative action policies are, in many ways, arbitrary and reflect a particular point of view rather than a neutral principle that incorporates social and historical contexts instead of denying their relevance in the making of law.

Any comprehensive OCR guidance on standards for evaluating title VI compliance can be informed by cases addressing the constitutionality of affirmative action programs under the equal protection clause of the 14th amendment.⁶¹² As one HHS civil rights attorney has

⁶⁰⁷ Ibid., p. 3.

⁶⁰⁸ Ibid.

⁶⁰⁹ Rush University, *Equal Access to Careers in Health*, p. 10.

⁶¹⁰ The Medical College of Georgia is another one of many medical schools that offers scholarships to women and minority medical students. Francis J. Tedesco, president, Medical College of Georgia, Augusta, GA, letter to Mireille Zieseniss, USCCR, Mar. 12, 1999 (re: information for health care project), p. 2. At Duke University full tuition scholarships are available each year to underrepresented minority students. Vicki Y. Saito, assistant vice chancellor for Health Affairs, Duke University Medical Center, Durham, NC, letter to Mireille Zieseniss, USCCR, Apr. 1, 1999 (re: information for health care project), attachment, "The Dean's Tuition Scholarships." The Northeastern Ohio University College of Medicine also offers scholarships aimed at increasing student diversity; these programs are based in the school's Office of Minority Affairs and Affirmative Action. Kenneth B. Durgans, assistant to the president for Minority Affairs and Affirmative Action, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 26, 1999 (re: information for health care project), enclosed brochure.

⁶¹¹ Rush University, *Equal Access to Careers in Health*, p. 17.

⁶¹² See *Regents of the University of California v. Bakke*, 438 U.S. 265 (1978). Four justices in *Bakke* found that "title VI prohibits only those uses of racial criteria that would violate the Fourteenth Amendment if employed by a State or its

stated, OCR is bound by the Constitution and would adopt constitutional standards in addressing any case involving vestiges of past discrimination.⁶¹³ For example, with regard to a medical school where vestiges of past discrimination have been found to exist, OCR would draw its guidance from constitutional standards.⁶¹⁴

In particular, OCR would draw guidance from equal protection standards.⁶¹⁵ Because OCR is bound by constitutional standards, it is important for OCR to provide guidance to medical schools on how it evaluates whether a school has been discriminating and how it determines whether an affirmative action plan meets constitutional standards. Therefore, OCR's guidance should address cases that may help to shape the standards OCR will apply in evaluating title VI compliance in the medical school admissions context. For example, OCR should address the standards for evaluating the constitutionality of affirmative action programs established in a recent court case, *Texas v. Hopwood*, in which a three judge panel of the fifth circuit found a law school's admissions policies impermissible under the equal protection clause.⁶¹⁶

Hopwood illustrates well the current hostility of the Federal judiciary toward affirmative action policies in the professional school context and its implications for OCR policy development with respect to medical school admissions programs. In *Hopwood*, a case brought by individuals claiming race discrimination resulting from

agencies." *Id.* at 328 (opinion of Brennan, White, Marshall, and Blackmun, J.J., concurring in the judgment in part and dissenting in part). See also 59 Fed. Reg. 8,756 (1994). U.S. Department of Education guidelines on minority recruitment under the "affirmative action" provisions of the title VI regulations state: "The Supreme Court has made clear that title VI prohibits intentional classifications based on race or national origin for the purpose of affirmative action to the same extent and under the same standards as the Equal Protection Clause of the Fourteenth Amendment. Thus, the Department's interpretation of the general language of the title VI regulations concerning permissible affirmative action is based on case law under both title VI and the Fourteenth Amendment." *Id.* at 8758-59.

⁶¹³ George Lyon, associate general counsel, HHS, Office of General Counsel, Civil Rights Division, telephone interview, Mar. 30, 1999, p. 1 (hereafter cited as Lyon interview).

⁶¹⁴ *Ibid.*, p. 1.

⁶¹⁵ *Ibid.*

⁶¹⁶ 78 F.3d 932 (5th Cir. 1996), *cert. denied*, 116 S. Ct. 2581 (1996).

an affirmative action policy, the fifth circuit held that the policy was unconstitutional.⁶¹⁷ The *Hopwood* court dismissed entirely the plurality opinion in *Regents of the University of California v. Bakke*,⁶¹⁸ a seminal Supreme Court case on affirmative action. In *Bakke*, five justices agreed that although a quota system violated the equal protection clause by discriminating on the basis of race, the University of California at Davis Medical School could not be enjoined from pursuing future admissions policies based on affirmative action principles.⁶¹⁹

In *Bakke*, Supreme Court Justice Powell, who voted with the plurality, wrote a separate opinion in which he stated that diversity is a sufficient justification for *limited* racial classification.⁶²⁰ In particular, he stated, "The attainment of a diverse student body . . . clearly is a constitutionally permissible goal for an institution of higher education."⁶²¹ He argued that diversity of minorities' viewpoints furthered "academic freedom," an interest under the Constitution. While acknowledging that "academic freedom" does not appear as a constitutional right, he argued that it had "long . . . been viewed as a special concern of the 1st Amendment."⁶²²

The *Hopwood* court rejected Justice Powell's opinion in *Bakke*, observing that his view on cultural diversity as a compelling interest had not represented the view of the majority of the Court.⁶²³ Applying a "strict scrutiny" analysis requiring the race-based classification at issue to "serve a compelling government interest" and to be "narrowly tailored to the achievement of that goal,"⁶²⁴ the *Hopwood* court refused to hold that student body diversity is a compelling state interest, stating that no Supreme Court case since

⁶¹⁷ 78 F.3d at 940.

⁶¹⁸ 438 U.S. 265 (1978).

⁶¹⁹ 438 U.S. at 307, 320 (plurality opinion).

⁶²⁰ *Id.* at 311-16.

⁶²¹ *Id.* at 311-12.

⁶²² *Id.* at 312.

⁶²³ 78 F.3d at 944.

⁶²⁴ 78 F.3d at 940 (citing *Adarand Constructors, Inc. v. Pena*, 515 U.S. 200, 235, 115 S. Ct. 2097, 2111, 2117 (1995)). The Supreme Court has stated that strict scrutiny is the proper standard to apply in determining the constitutionality of affirmative action programs, regardless of whether they are Federal, State, or local government programs. *Adarand Constructors, Inc. v. Pena*, 515 U.S. at 227, 115 S. Ct. 2097, 2113 (1995).

Bakke has accepted diversity as such under a strict scrutiny analysis.⁶²⁵ Nonetheless, the Supreme Court has not expressly held that diversity is not a compelling interest, and as one fifth circuit judge wrote in special concurrence to *Hopwood*, "If *Bakke* is to be declared dead, the Supreme Court . . . should make that pronouncement."⁶²⁶

Even more disheartening is the *Hopwood* court's significant narrowing of the ambit of the term "past discrimination" in a fashion that one commentator has referred to as straining "the bounds of reason and prevailing precedent."⁶²⁷ According to the court in *Hopwood*, the only persuasive evidence of past discrimination would be a record of official racial discrimination by the law school itself.⁶²⁸ Therefore, the only remedial racial classifications that could be justified would be those used to redress present harm resulting from past discriminatory practices by the law school itself, rather than other "units" within the Texas public school system.⁶²⁹

Having decided that only evidence of discrimination within the law school itself would suffice, the court rejected the plaintiff's use of the underrepresentation of minorities in the law school's student body as evidence of present effects of past discrimination.⁶³⁰ The court relied on a Supreme Court decision, *City of Richmond v. J.A. Croson Co.*,⁶³¹ in which the Court determined that the proper scope for evaluating the effects of past discrimination was not the entire construction industry but rather limited to the Richmond construction industry.⁶³²

However, analogizing to the higher education context, it seems that the proper scope might not be limited to just the law school itself but might just as logically include other educational institutions, such as the State's public primary and secondary schools. As one commentator noted,

"By applying the Court's reasoning in government employment contract situations to the facts in *Hopwood*, the Fifth Circuit ignored characteristics unique to the educational context."⁶³³ For example, the district court in *Hopwood*⁶³⁴ identified the relationship between the State's higher education system and the elementary and secondary systems as playing a role in the perpetuation of past discrimination. The court observed, "The State's institutions of higher education are inextricably linked to the primary and secondary schools in the system."⁶³⁵ . . . The effects of the State's past de jure segregation in the educational system are reflected in the low enrollment of minorities in professional schools, including the law school."⁶³⁶

The district court also reasoned that the denial of opportunities for higher education to a generation of minority parents bears a clear causal connection to the diminished educational attainment of the present generation.⁶³⁷ The validity of the district court's observation is borne out in statements made by the Association of American Medical Colleges and other organizations familiar with trends in medical school matriculation. For example, a former president of the AAMC stated:

We cannot produce underrepresented minority medical applicants. We cannot produce underrepresented minority medical students if there is an insufficient number who are applying to our schools, graduating from college, or even finishing high school with sufficient skills to enable them to survive a premedical course of study. . . . The magnitude of the increases in minority medical students that are needed can only result from substantial growth in the size and enhancement in the quality of the applicant pool. This will not be accomplished without programmatic emphasis during the high school and early undergraduate college years.⁶³⁸

⁶²⁵ 78 F.3d at 944.

⁶²⁶ 78 F.3d at 963 (Wiener, J., specially concurring).

⁶²⁷ Therese M. Goldsmith, "Note: *Hopwood v. Texas*: The Fifth Circuit Further Limits Affirmative Action Educational Opportunities," *University of Maryland Law Review*, vol. 56 (1997), pp. 273, 286.

⁶²⁸ 78 F.3d at 954.

⁶²⁹ 78 F.3d at 953-54.

⁶³⁰ *Id.*

⁶³¹ 488 U.S. 469 (1989).

⁶³² 488 U.S. at 500 (1989).

⁶³³ Goldsmith, "Note: *Hopwood v. Texas*," p. 287.

⁶³⁴ *Hopwood v. Texas*, 861 F. Supp. 551, 561-62 (W.D. Tex. 1994), *rev'd and remanded in part, and appeal dismissed in part*, 78 F.3d 932 (5th Cir. 1996), *cert. denied*, 116 S. Ct. 2581 (1996).

⁶³⁵ 861 F. Supp. at 571.

⁶³⁶ 861 F. Supp. at 572.

⁶³⁷ 861 F. Supp. at 573 (citations omitted).

⁶³⁸ Robert G. Petersdorf, M.D., president, Association of American Medical Colleges, "Not A Choice, An Obligation," Presented at the plenary session of the 102nd meeting of the

Unfortunately, and perhaps most troubling of all, the fifth circuit refused to recognize a causal relationship between the law school's race-based admissions program and present harm caused by past discriminatory practices by the Texas public school system.⁶³⁹ In finding no causal relationship, the *Hopwood* court relied in part on *Croson* in which the Supreme Court explained, "Like the claim that discrimination in primary and secondary schools justifies a rigid racial preference in medical school admission, an amorphous claim that there has been past discrimination in a particular industry cannot justify the use of an unyielding racial quota."⁶⁴⁰ Similarly, in *Bakke*, a plurality of the Supreme Court affirmed the California Supreme Court's holding that the admissions policy of the University of California at Davis Medical School was invalid under the 14th amendment.⁶⁴¹ The Court observed that "[b]oth courts below characterized [the admissions policy] as a 'quota' system."⁶⁴² However, the terms "affirmative action" and "quota system" are in no way synonymous; nor is there any requirement in OCR's title VI regulations for recipients to rely on quota systems in developing affirmative action policies.⁶⁴³ It seems the most pressing issue with respect to affirmative action is clarifying what the terms mean.

Reacting to the fifth circuit's decision in *Hopwood*, the Association of American Medical Colleges stated:

This legal action . . . threatens to turn back the clock on some of the most important civil rights advances made in this country over the last 25 years. If these efforts to eliminate affirmative action policies remain unchallenged, the AAMC projects that minority enrollment in our nation's medical school classes (with the exception of Asian Americans) would revert to levels characteristic of pre-Civil Rights eras.⁶⁴⁴

Association of American Medical Colleges, Washington, DC, Nov. 10, 1991.

⁶³⁹ 78 F.3d at 955.

⁶⁴⁰ 488 U.S. at 499.

⁶⁴¹ 438 U.S. 265, 320.

⁶⁴² *Id.* at 287.

⁶⁴³ See 45 C.F.R. § 80.3(b)(6)(i)-(ii) (1998). See generally 45 C.F.R. § 80 (1998).

⁶⁴⁴ AAMC, "Affirmative Action in Medicine," p. 1.

OCR's Title VI Affirmative Action Regulatory Provisions

In light of judicial decisions severely curtailing the use of "affirmative action" policies in State-run professional school admissions programs, illustrated by the *Hopwood* case, OCR must provide detailed guidance targeted to medical school programs receiving HHS funds. As of July 1999, OCR's efforts to implement title VI's affirmative action mandate consist of two brief, rather vague regulatory provisions identifying affirmative action as a means of ensuring title VI compliance.

The first provision states that "[i]n administering a program regarding which the recipient has previously discriminated against persons on the ground of race, color, or national origin, the recipient must take affirmative action to overcome the effects of prior discrimination."⁶⁴⁵ The second provision states that even in the absence of such prior discrimination, recipients "may take affirmative action to overcome the effects of conditions which resulted in limiting participation by persons of a particular race, color or national origin."⁶⁴⁶ Since only schools that have previously engaged in discrimination are *required* to develop affirmative action policies, many recipient medical schools are under no obligation under the regulation to take such affirmative action. Any steps they choose to take to ensure minority participation in their programs are purely voluntary.⁶⁴⁷

These regulatory provisions are perfunctory. Moreover, OCR has no guidance for HHS-assisted medical schools, which are subject to constitutional scrutiny. Without clearer, more detailed, comprehensive guidance targeted spe-

⁶⁴⁵ 45 C.F.R. § 80.3(b)(6)(i) (1998).

⁶⁴⁶ 45 C.F.R. § 80.3(b)(6)(ii) (1998) (emphasis added).

⁶⁴⁷ However, the OCR regulations contain an explanatory regulation for this second provision. They state:

Even though an applicant or recipient has never used discriminatory policies, the services and benefits of the program or activity it administers may not in fact be equally available to some racial or nationality groups. In such circumstances, an applicant or recipient may properly give special consideration to race, color, or national origin to make the benefits of its program more widely available to such groups, not then being adequately served. For example, where a university is not adequately serving members of a particular racial or nationality group, it may establish special recruitment policies to make its program better known and more readily available to such group, and take other steps to provide that group with more adequate service. *Id.* § 80.5(j) (1998).

cifically toward medical school recipients, both State-run and private, OCR is not fulfilling its responsibilities to clarify the requirements of the nondiscrimination provisions in the title VI statute and its regulations. As one commentator has noted:

[F]ederal law requires HHS to supplement the general title VI regulations with more specific guidelines for each program to which it extends assistance. . . . These guidelines are intended to provide the specificity lacking in the general title VI regulations—to give examples of prohibited practices in the context of particular programs, to outline required and suggested remedial action, and to provide data collection requirements. . . .⁶⁴⁸

Currently, OCR's title VI regulatory provisions identifying affirmative action as a means of "administering a program regarding which the recipient has previously discriminated" and "overcoming the effects of conditions which resulted in limited participation" do not provide sufficient clarity on the meaning of these terms. In particular, they do not offer any guidance on the standards OCR will use to evaluate medical schools' admissions policies, both those that have affirmative action based policies and those that do not. OCR should clarify its meaning for certain key terminologies in its "affirmative action" regulations under title VI. In particular, OCR must define clearly, within the parameters set by case precedent, the term "affirmative action" itself, as well as "past discrimination," and "limiting participation."

The *Bakke* case informs potential OCR guidelines for privately run medical schools receiving Federal funding because *Bakke* is the only case in which the Supreme Court has mentioned the two affirmative action provisions in the title VI regulations. In *Bakke*, four Justices observed:

[I]t is most significant that the Department of Health, Education, and Welfare (HEW), which provides much of the federal assistance to institutions of higher education, has adopted regulations *requiring* affirmative measures designed to enable racial minorities which have been previously discriminated against by a federally funded institution or program to overcome the effects of such actions and *authorizing* the voluntary undertaking of affirmative-action programs by feder-

ally funded institutions that have not been guilty of prior discrimination in order to overcome the effects of conditions which have adversely affected the degree of participation by persons of a particular race.⁶⁴⁹

These Justices reinforced their endorsement of the regulations in stating:

It would be difficult to explain from the language of title VI, however, much less from its legislative history, why the statute *compels* race-conscious remedies where a recipient institution has engaged in past discrimination but *prohibits* such remedial action where racial minorities, as a result of the effects of past discrimination imposed by entities other than the recipient, are excluded from the benefits of federally funded programs. . . . This interpretation of title VI is fully consistent with the statute's emphasis upon voluntary remedial action and reflects the view of an agency responsible for achieving its objectives.⁶⁵⁰

Because the protections of the title VI statute are co-extensive with that of the equal protection clause,⁶⁵¹ private medical schools receiving Federal funds would potentially be subjected to strict scrutiny equal protection analysis under the title VI regulations.⁶⁵² If the Court were to review the legitimacy of an affirmative action program under the title VI statute or OCR's title VI regulations, equal protection jurisprudence would inform its analysis.⁶⁵³ As it evaluated the affirmative action policies of private schools, the Court probably would consider how agencies have interpreted the issue by studying policy

⁶⁴⁹ 438 U.S. at 343 (opinion of Brennan, White, Marshall, and Blackmun, J.J., concurring in the judgment in part and dissenting in part).

⁶⁵⁰ 438 U.S. at 344–45 (opinion of Brennan, White, Marshall, and Blackmun, J.J., concurring in the judgment in part and dissenting in part).

⁶⁵¹ See 438 U.S. at 352–53 (opinion of Brennan, White, Marshall, and Blackmun, J.J., concurring in the judgment in part and dissenting in part).

⁶⁵² See Nondiscrimination in Federally Assisted Programs: Title VI of the Civil Rights Act of 1964, 59 Fed. Reg. 8756, 8758–59 (1994) (stating that "the Supreme Court has made clear that Title VI prohibits intentional classifications based on race or national origin for the purpose of affirmative action to the same extent and under the same standards as the Equal Protection Clause of the Fourteenth Amendment," and not distinguishing between State-run and private colleges in its application of title VI affirmative action policies).

⁶⁵³ The Supreme Court has held that affirmative action efforts under title VI are permissible only to the extent allowable under the equal protection clause. *Bakke*, 438 U.S. 265, 287 (1978).

⁶⁴⁸ Watson, "Health Care in the Inner City," pp. 1670–71.

guidance documents. Unfortunately, however, OCR has never issued any policy guidance on affirmative action programs in medical schools, failing to avail itself of the opportunity to influence the Court in this important area.

Therefore, in developing guidance, OCR should address several factors relating to affirmative action programs conducted by medical schools. These include the narrow ambit carved out by the Court in *Adarand* for conducting affirmative action programs, the constitutionality of the second of OCR's two affirmative action provisions in its title VI regulations in the context of State-run institutions, and the reach of the regulations for private medical schools receiving Federal funding. It appears that almost any affirmative action plan undertaken by a State-run medical school without sufficient evidence of a past history of discrimination by that school would be invalidated under the Constitution. Therefore, in the context of State-run institutions, the constitutionality of the second of OCR's two affirmative action provisions in its title VI regulations probably would be called into question if subjected to a judicial interpretation.⁶⁵⁴ However, the outcome of a case involving a private school's use of affirmative action is less clear.

The Federal Government already has developed guidance that should assist policy preparation by OCR on the title VI affirmative action provisions in the medical school admissions context. For example, in 1994 the Department of Education (DOEd) issued policy guidance, published in the *Federal Register*, addressing the applicability of the title VI statute's and regulations' nondiscrimination requirement to student financial aid that is awarded, at least in part, on the basis of race or national origin.⁶⁵⁵ Although this guidance will probably need revisions in the wake of the *Adarand* decision, it provides a good example of the kinds of issues OCR should address, perhaps in tandem with DOEd's Office for Civil Rights. The DOEd guidance specifically stated:

The permissibility of awarding student financial aid based, in whole or in part, on a student's race or national origin involves an interpretation of the [title VI

regulatory] provisions concerning affirmative action . . . Thus, the Department's interpretation of the general language of the title VI regulations concerning permissible affirmative action is based on case law under both title VI and the Fourteenth Amendment.⁶⁵⁶

This point is key for any future policy guidance OCR will develop to address medical school admissions. OCR must address these issues in developing guidance filling in the details for these regulatory provisions. OCR's guidance should identify criteria for determining whether a program is permissible for State-run and private recipients. This guidance should include illustrative examples of the most effective ways of developing these kinds of programs. For example, with regard to the second provision, which merely states that a school that has not discriminated can undertake affirmative action, a hypothetical case can illustrate the need for further guidance for medical school recipients on these provisions. OCR could use an example such as: OCR has entered into a settlement agreement with a private medical school that has never intentionally discriminated but which has admissions policies that are creating a disparate impact on minority applicants. OCR and the medical school resolve the compliance issue with a negotiated settlement in which the school agrees to undertake an affirmative action plan. A white male applicant refused admission because of this program potentially could sue under the nondiscrimination provision of title VI.

Implementing Title VI Affirmative Action Requirements

A review of literature and case law addressing efforts to increase minorities among students admitted to professional school suggests two broad themes: first, the need for OCR to establish clear guidelines on affirmative action plans and to address more fully through policy and enforcement activities the issue of minority admissions to medical schools, second is the need for HHS OCR to work with DOEd/OCR, with which it shares enforcement authority for title VI, to ensure that minority students in elementary and secondary schools are provided with the tools necessary for them to compete successfully with their nonminority peers at the college and professional school levels. Together, the two

⁶⁵⁴ Lyon interview, p. 2.

⁶⁵⁵ 59 Fed. Reg. 8,756 (1994).

⁶⁵⁶ *Id.* at 8,758-59.

agencies can work on developing new directions in their efforts to reach this goal, perhaps collaborating on guidelines for medical school admissions and the use of affirmative action policies in such programs.

The need for guidelines addressing title VI compliance in this context is well demonstrated in research studies and other commentary relating to medical school admission policies. A review of the work of commentators and researchers reveals that barriers to ensuring non-discrimination in medical school admissions remain major concerns across a broad spectrum of stakeholders, including medical professionals, health care providers, policymakers, and of course the beneficiaries of HHS-funded health care recipients' programs and activities.

OCR has an obligation to ensure that title VI and its regulations are fully implemented through policy guidance or guidelines published in the *Federal Register*. OCR should focus its attention on medical schools, both State-run and private, relying on tools such as policy guidance to ensure that medical school admissions and study remain free of discrimination. In seeking to ensure civil rights compliance among medical schools that are recipients of HHS funding, OCR must develop the kind of comprehensive, detailed policy guidance that can provide medical school administrations with the information they need to ensure that they are complying with nondiscrimination mandates and undertaking proactive efforts to ensure equal access to education in medicine for racial/ethnic minorities and women.

OCR must develop this guidance to ensure that medical schools are fully aware of their obligations under title VI, particularly the implications of such factors as past discrimination on maintaining title VI compliance. OCR must provide a cohesive discussion that includes a review of the relevant case law and its implications for title VI compliance. OCR might provide guidance on ways in which medical schools may develop policies to comply with title VI and its regulations.

In addition, because "affirmative action" is such a famously ambiguous term with many different meanings attached to it, OCR *must* provide some form of guidance defining clearly what it means by affirmative action. Similarly OCR should provide examples of cases where the

courts have found particular institutions to have engaged in prior discrimination, so that all medical schools will better understand the extent of their obligations under the title VI regulations. In addition, OCR must ensure that medical school recipients are fully aware that the title VI regulations include these provisions. Moreover, OCR must ensure that top administrative and other decisionmaking personnel at these schools fully understand and appreciate OCR's objectives in encouraging proactive efforts to include minorities and women among their student populations.⁶⁵⁷

OCR therefore must include in its guidance to medical schools a discussion on, among other things, the kinds of affirmative action programs that are permissible; the acceptable rationale for conducting affirmative action based admissions programs; the scope for evaluating the effects of past discrimination; and the evidence required to show past discrimination, e.g., disparities in numbers of racial/ethnic minorities represented in the student population. In particular, OCR should address more current ideas for implementing affirmative action programs, such as recruiting socially and economically disadvantaged students, with race-based presumptions in identifying disadvantaged individuals.

Hill-Burton Act: Rulemaking and Policy Development

Overall Lack of Policy Development

HHS has provided regulations implementing the Hill-Burton Act,⁶⁵⁸ and the nondiscrimination provision under the Hill-Burton Act is contained in these regulations. Known as the "community service assurance," the regulatory provision states:

In order to comply with its community service assurance, a facility shall make the services provided in the facility or portion thereof constructed, modernized, or converted with Federal assistance under title VI or XVI of the Act available to all persons residing . . . in the facility's service area without discrimination on the ground of race, color, national origin, creed, or any other ground unrelated to an individual's need for the service of the availability of the needed service in the facility.⁶⁵⁹

⁶⁵⁷ See USCCR, *The Health Care Challenge*, vol. I, chap. 2.

⁶⁵⁸ 42 U.S.C. § 291c(a)-(e) (1994).

⁶⁵⁹ 42 C.F.R. § 124.603(a)(1) (1998).

This is one of two provisions in the Hill-Burton regulations containing a nondiscrimination requirement. The second provision requires nondiscrimination against beneficiaries of government third-party payors.⁶⁶⁰ There is no further mention in the regulations of the civil rights component of the Hill-Burton Act. At a minimum, an appendix to the regulations containing interpretive guidance on this provision would be helpful to OCR investigative staff and recipients of Hill-Burton funds in ensuring compliance with its mandate. Interpretive guidance could provide the kinds of detailed analysis and examples currently lacking in the regulations and OCR policy guidance. A discussion addressing the term “any other ground unrelated” would be particularly useful since it appears to go beyond the scope of title VI.

OCR has not developed any policy guidance on Hill-Burton-related enforcement issues in many years. The most recent guidance documents that OCR has provided on Hill-Burton issues were disseminated in 1981 and 1988. For example, in 1981 OCR disseminated a guidance memorandum to regional staff on conducting compliance reviews for Hill-Burton facilities to determine whether they are in compliance with their community service assurances obligations.⁶⁶¹ Another memorandum, developed in 1988, offers very thorough guidance for investigators on processing patient dumping complaints.⁶⁶²

At least one commentator has noted the negative effect the lack of current policy guidance has had on HHS enforcement of Hill-Burton nondiscrimination requirements.⁶⁶³ For example, she believes that the provision requiring nondiscrimination against beneficiaries of government third-party payors has never really been used. There is no policy guideline, so it's never been enforced. OCR has no familiarity or

⁶⁶⁰ *Id.* § 124.603(c) (1998).

⁶⁶¹ Virginia P. Apodaca, acting deputy director, Office of Compliance and Enforcement, memorandum to regional directors, Regions I–X, OCR, HHS, June 30, 1981 (re: a guide to planning the Hill-Burton community services compliance review) (hereafter cited as Apodaca memorandum).

⁶⁶² See Audrey F. Morton, director, OCR, HHS, memorandum to OCR regional managers, May 4, 1988 (re: instructions for processing cases involving patient dumping issues) (hereafter cited as OCR Instructions—Dumping Issues).

⁶⁶³ Lado interview, pp. 24–25.

expertise with it.⁶⁶⁴ To its credit, between 1998 and 1999, OCR developed a draft chapter discussing Hill-Burton enforcement in the substantive compliance manual on which it has begun work.⁶⁶⁵

Hill-Burton Compliance in Specific Contexts *Discriminatory Staff Physician Admissions Policies*

The community services subpart of the Hill-Burton Act proscribes discrimination against patients in a facility's service area on any ground unrelated to the need for medical service.⁶⁶⁶ One of the strategies hospitals have invoked to filter out poor and minority patients is to adopt admissions policies that require the patient's primary care physician have staff privileges at the facility.⁶⁶⁷ Such staff physician admissions policies often create barriers to access for minorities.⁶⁶⁸ The Hill-Burton regulations attempt to address this specific practice in the subpart.⁶⁶⁹

Antidumping Provision

Patient “dumping” occurs when an emergency facility refuses to treat a patient based on inability to pay or other factors not related to necessity for care. This phenomenon has been associated with race discrimination because emergency patients are disproportionately minority. Section 124.603 (b) of the Hill-Burton regulations prevents a facility from denying emergency services to any person who resides (or, if the facility received title XVI funds, is employed) in the facility's service area on the ground that the person is unable to pay for services.⁶⁷⁰ Once the patient has been treated, and the appropriate medical personnel have determined that such

⁶⁶⁴ *Ibid.*, p. 24

⁶⁶⁵ Garrison and Guerrero interview, p. 3; O'Brien and Mackey interview, p. 5 (statement of Mackey). See “Antidumping Provision,” below.

⁶⁶⁶ 42 C.F.R. §§ 124.601–607 (1998). For more discussion of the community service provision, see “A History of Federal Civil Rights and other Statutes Addressing Access to Health Care,” above.

⁶⁶⁷ See generally Rosenbaum, et al., “Civil Rights in a Changing Health Care System.”

⁶⁶⁸ See generally *ibid.*

⁶⁶⁹ 42 C.F.R. § 124.603(d) (1998). See “Title VI Compliance in Specific Contexts,” above, for a discussion of this issue.

⁶⁷⁰ *Id.*; see also HHS, OCR, Substantive Compliance Manual, draft, Jan. 25, 1999, “Hill-Burton Chapter” (hereafter cited as OCR, Draft Hill-Burton Chapter).

action would not put the patient at risk for substantial deterioration in medical condition, the facility may transfer or discharge the patient.⁶⁷¹ OCR Region VI has been particularly active in addressing patient dumping issues.⁶⁷²

The Emergency Medical Treatment and Active Labor Act (EMTALA) was passed in 1985.⁶⁷³ Pressure was then exerted on OCR to develop comprehensive investigative procedures for the Hill-Burton antidumping provision, to avoid duplication of effort in investigating dumping cases among the Health Care Financing Administration (HCFA), the Office of the Inspector General, and OCR.⁶⁷⁴ In 1988 OCR disseminated indepth instructions for investigating Hill-Burton complaints and compliance reviews. Since then, the prominence of the antidumping provision of the Hill-Burton Act has decreased somewhat, because most dumping complaints are filed with HCFA under EMTALA.⁶⁷⁵ Every hospital that participates in medicare and offers emergency services is subject to EMTALA.⁶⁷⁶ The Hill-Burton antidumping provision only reaches facilities that have received Hill-Burton funds. Nonetheless, OCR still receives and investigates Hill-Burton complaints, and the HCFA investigative procedural manual requires HCFA program officials to notify OCR regional offices when they receive an antidumping case.⁶⁷⁷

OCR's 1988 Dumping Investigation Instructions

To ensure that antidumping cases are correctly investigated, OCR issued a detailed instruction packet to its regional staff in 1988.⁶⁷⁸ The packet provided a wealth of materials to assist investigators. For instance, the packet included such sections as "Guidelines for Handling Patient Dumping Cases," a Model Investigative

Plan, "Suggested Investigative Approaches," as well as worksheets, forms, and model memos for referring cases to other agencies.⁶⁷⁹ The packet provided a framework for processing and investigating dumping cases from receipt of the complaint to case closure. It elucidated the jurisdictional issues used to determine whether OCR may investigate complaints, as well as outlining the elements affecting the referral of cases to HCFA and the Office of Inspector General.⁶⁸⁰ The Model Investigative Plan recommends the information to be gathered and lists potential sources.

Perhaps the most informative section of the instructions is that on suggested investigative approaches. For each type of data listed in the Model Investigative Plan, the Suggested Investigative Approaches section provides three paragraphs explaining the purpose for collecting the data and how the data are used. For example, the Model Investigative Plan suggests that the investigator collect ambulance logs. In Suggested Investigative Approaches, two paragraphs detail how to analyze those logs. The section states that the logs allow identification of patients who were transferred to other hospitals, the personnel who authorized the transfers, and what the reasons given for the transfer were.⁶⁸¹ It explains that the information assists in identifying wrongly transferred patients. The section continues that such information is also helpful in discovering possible patterns of discrimination by each physician, by illness, race, income, or other category.⁶⁸²

When the hospital itself provides ambulance services, the section instructs the investigator to review ambulance logs to document points of origin, focusing on the geographic area and whether patients are routinely delivered to that hospital or to other hospitals as well. If the ambulance service provided by the hospital delivers to other hospitals, the instructions ask the investigator to identify patterns of delivery based on point of pickup, type of medical emergency,

⁶⁷¹ 42 C.F.R. § 124.603(b)(2) (1998); *see also* OCR, Draft Hill-Burton Chapter.

⁶⁷² O'Brien and Mackey interview, p. 7.

⁶⁷³ *See* 42 U.S.C. § 1395dd(a)-(c) (1994). *See also* Pollack interview.

⁶⁷⁴ *See* OCR Instructions—Dumping Issues.

⁶⁷⁵ *See* Pollack interview, p. 6.

⁶⁷⁶ 42 U.S.C. § 1395dd(e)(2) (1994).

⁶⁷⁷ *See* HHS, Health Care Financing Administration, Manual, "Guidelines for Hospital Emergency Care," 42 C.F.R. § 489.24, A406(a) (1998) (hereafter cited as HCFA Manual, "Guidelines for Hospital Emergency Care").

⁶⁷⁸ *See* OCR Instructions—Dumping Issues.

⁶⁷⁹ *See* *ibid.*, table of contents. Some cases are referred to HCFA or the Office of Inspector General.

⁶⁸⁰ *See* OCR, Instructions—Dumping Issues, "Guidelines for Handling Patient Dumping Cases"; "Model Investigative Plan"; "Suggested Investigative Strategies."

⁶⁸¹ OCR, Instructions—Dumping Issues, p. 12.

⁶⁸² *Ibid.*

race/ethnicity, method of payment, etc. The section also instructs investigators to determine the professional responsible for deciding to which facility patients are delivered. Then the investigator must compare these findings with other sources documenting patient transfers for consistency.⁶⁸³

The comprehensiveness of the dumping instructions illustrates the high quality that OCR can produce for high-profile issues. If other policy could be promulgated with the same depth of thought and attention to detail, OCR regional staff would have sound guidance in all areas of investigation.

Draft Substantive Compliance Manual

The Hill-Burton chapter of OCR's draft substantive compliance manual includes a subchapter on "Specific Hill-Burton Issues" that contains an indepth treatment of the dumping issue.⁶⁸⁴ The subchapter includes the language of the relevant section of the statute; a discussion outlining what the statute proscribes, as well as some significant issues involved in enforcing the provisions; and sections focusing on the types of information that investigators should gather for each issue, including suggested questions and potential data sources.

The discussion contains a general treatment of the antidumping provision, as well as subsections focusing on emergency services, discharge, and transfer. The introductory section explains what is prohibited and which facilities are governed by the statute. It also attempts to clarify anticipated areas of confusion. For example, the section states that the requirement to provide emergency services applies to "all Hill-Burton facilities that provide emergency services whether or not they have an obligation to provide free care under the uncompensated service assurance."⁶⁸⁵ This reminds the reader that facilities that have already met their uncompensated care obligations are still obligated under the antidumping section. The discussion section also emphasizes that "inability to pay" includes patients who do not have health insurance or who do not have enough cash for a deposit.⁶⁸⁶

⁶⁸³ Ibid.

⁶⁸⁴ OCR, Draft Hill-Burton Chapter, pp. 10-16.

⁶⁸⁵ Ibid., p. 10.

⁶⁸⁶ Ibid.

The second section in the "Specific Hill-Burton Issues" subchapter is titled "Denial of Emergency Services to Persons Unable to Pay."⁶⁸⁷ It begins with a definition of emergency services.⁶⁸⁸ The section refers to an excerpt from OCR's January 19, 1981, emergency services policy that states "[e]mergency services are those services which are necessary to prevent the death or serious impairment of the health of the individual, and which, because of the threat to the life or health of the individual, necessitate the use of the most accessible hospital (available and) equipped to furnish such services."⁶⁸⁹ The emergency services section warns that a facility does not have to have an organized emergency room to be covered by the law: it merely must have the capacity to provide emergency services.⁶⁹⁰ Moreover, all necessary services that could be provided by the acute care facility are required to be provided.⁶⁹¹ The section also describes the procedures for emergency-patient intake and treatment that occur at the typical emergency care facility,⁶⁹² lists examples of phases in the emergency process in which violations might occur, and suggests that the ambulance and hospital logs and records might contain written documentation of a violation.

The emergency services section also contains a subsection on transfers and discharges that

⁶⁸⁷ Ibid.

⁶⁸⁸ Ibid., pp. 10-16.

⁶⁸⁹ Ibid., p. 10 (quoting David Chavkin, deputy director for Program Development, memorandum to John Bynoe, regional director, Region I, OCR, HHS, Jan. 19, 1981, p. 2 (re: emergency services under Hill-Burton)) (hereafter cited as OCR, Emergency Services memorandum).

⁶⁹⁰ Ibid. If the facility is licensed by the State, or accredited by JCAH to provide emergency services, it has the capacity.

⁶⁹¹ Ibid.

⁶⁹² Decisions are usually made by different professionals at different stages. If a patient arrives by ambulance, the ambulance crew records the patient in their log. The patient is then recorded in the emergency room log. A triage system is used to prioritize the patients, to determine the order in which patients will be treated. Respiratory or circulatory problems receive highest priority. Once the patient is in a treatment room, a nurse takes the patient's vital signs and establishes the general condition. The nurse records this information on a treatment form, and a physician is called if necessary. The physician determines what course of treatment will follow. For example, the patient may be admitted as an inpatient, the physician may request the services of another physician, or the patient may be transferred or discharged. Ibid., p. 12.

details which transferring and discharge procedures are allowed and which are prohibited.⁶⁹³ For example, a facility may transfer or discharge a patient who is unable to pay once that patient has received emergency treatment.⁶⁹⁴ However, transfer or discharge may not be based upon race, national origin, method of payment, or lack of staff privileges of the patient's primary care physician.⁶⁹⁵ The decision to transfer or discharge must be made by the medical professional who is normally responsible for making such decisions, and the facility to which the patient is transferred must be capable of providing the needed services.⁶⁹⁶

The section on emergency services also suggests questions for investigators to ask about emergency services and transfer and discharge.⁶⁹⁷ Under emergency services, investigators are encouraged to inquire into such subjects as: (1) the types of emergency services the facility provides, (2) whether the medical personnel at the facility are aware of the antidumping law, (3) which emergency services are available in the emergency room and which services are available elsewhere in the facility, (4) whether the facility denies or delays care to patients that cannot tender an advance deposit for the emergency care, (5) and whether there are posted signs that indicate that an advance deposit is required.⁶⁹⁸

The suggested questions for transfer or discharge are: (1) who decides to transfer or discharge patients from the emergency facility, (2) which criteria are used to judge whether to transfer or discharge, (3) the number of patients transferred or discharged during the last year and the reasons for transfer or discharge, (4) the names of the facilities to which patients were transferred or discharged, (5) whether the appropriate medical personnel made the transfer decisions, and (6) whether there were any pa-

tients subjected to substantial risk or deterioration in medical condition.⁶⁹⁹

Finally, the emergency services section of the subchapter lists possible data needs and sources for investigators to use in antidumping cases.⁷⁰⁰ For investigating denial of emergency services, the section suggests: (1) collecting copies of all emergency services policies and procedures (including emergency treatment forms), payment policies (including advance deposit requirements), emergency room logs, ambulance logs, trip reports, transfer memoranda, and medical staff bylaws; (2) obtaining lists of on-call physicians, emergency medical staff, and all contracted services for the emergency room; (3) interviewing emergency room doctors, admissions staff and doctors, and community contacts; (4) collecting minutes from emergency department committee meetings, medical staff meetings, (5) analyzing data from the community service assurance report; and (6) determining the method of payment for all individuals requesting emergency services.⁷⁰¹

For transfer and discharge issues, the section recommends: (1) collecting copies of all the facility's policies, procedures, and instructions on transferring and discharging emergency services; (2) obtaining lists of physicians who are on-call to provide stabilizing treatment, and of medical personnel responsible for deciding whether patients are transferred or discharged; (3) for the period in question, obtaining lists of transferred or discharged patients, along with their medical records and method-of-payment information; and (4) interviewing medical personnel responsible for transferring or discharging patients, and community contacts.⁷⁰²

Overall, the subchapter's section on denial of emergency services confronts the major points of concern for the antidumping issue. It describes the prohibitions of the antidumping section of the Hill-Burton regulations, attempting to anticipate and clarify potential areas of confusion. It describes the basic process of emergency intake and treatment at most facilities. Finally, it suggests lines of questioning and possible data sources.

⁶⁹³ *Ibid.*, pp. 13-16.

⁶⁹⁴ *Ibid.*, p. 13

⁶⁹⁵ *Ibid.*

⁶⁹⁶ *Ibid.* Hospitals that are accredited by JCAH must make transfers of patients in accordance with their community-based emergency plan, and must obtain the consent of the patient. *Ibid.*

⁶⁹⁷ *Ibid.*, pp. 14-15.

⁶⁹⁸ *Ibid.*, p. 14.

⁶⁹⁹ *Ibid.*

⁷⁰⁰ *Ibid.*, pp. 15-16.

⁷⁰¹ *Ibid.*, p. 15.

⁷⁰² *Ibid.*, p. 16.

However, like the other Hill-Burton subchapters, it stops short of providing sufficient, substantive guidance required for a comprehensive investigation. First, the subchapter lacks a background element that illustrates the context in which emergency services occur, and the factors that can lead to patient dumping. For example, psycho-social elements may affect a triage nurse's ability to rank patients objectively in the emergency queue. A nurse who has been part of a triage unit for many years in a metropolitan area may associate particular medical conditions with particular races or classes, to the extent that the nurse's judgment of the seriousness of a patient's condition may be impaired. Investigators need to be aware of this tendency in evaluating patient referral issues.

Second, the subchapter avoids grappling with one of the most difficult, yet crucial points of concern: the definition of an emergency. Although it refers to an earlier emergency services policy memorandum⁷⁰³ and quotes the definition provided therein, the subchapter itself does not expand on the concept. The policy services memorandum also fails to adequately expand on the subject. The memorandum states that in determining whether an emergency exists for Hill-Burton purposes, the fact that a complainant survived an emergency after being denied services, does not decide the case.⁷⁰⁴ Rather, the memorandum asserts, the question is whether trained medical personnel should have believed, in light of the patient's condition, that services were necessary to prevent the death or serious impairment of the health of the individual.⁷⁰⁵ The memorandum then provides specific guidance for determining whether a woman in labor requires emergency services: "A woman giving birth for the first time should be admitted when her contractions are regular, progressively hard and closer and occurring at about five minute intervals."⁷⁰⁶ The memorandum also provides guidance for women who have given birth previously.⁷⁰⁷ Unfortunately, however, there are many types of medical emergencies aside from women in active labor, but the emergency serv-

ices policy memorandum addresses only that scenario.

Several issues complicate the determination of what constitutes an emergency. For example, managed care organizations may use a different definition of emergency than what OCR sees as being required under the Hill-Burton regulations. To deter patients from using the emergency room for primary care, MCOs often include a strict definition of "emergency" in the health care plan.⁷⁰⁸ In a significant number of instances, MCOs have used this strict definition to refuse to pay for emergency services by contending that the medical condition was not an "emergency."⁷⁰⁹ If the patient does not meet the MCO's definition, payment for services are denied.⁷¹⁰ Strict definitions such as these should not be used by emergency personnel.

Another context that illustrates the lack of adequate definition is one that includes a "desensitized" triage nurse such as that described above. If such a medical professional has significant leeway in deciding whether a patient's symptoms are critical, the patient could suffer discrimination based upon either race or inability to pay. The generalized definition of "emergency" supplied by HHS does not confront this specter. Although it would be difficult to develop a lengthy catalogue of symptoms that would constitute an emergency, there may still be approaches for implementing clearer standards. If an emergency medical manual were selected as the standard, this would supply more specific benchmarks for investigators to use in their work. Expert physicians from the Public Health Service could serve as medical interpreters for the investigators.

Third, the recommended questions and data sources are a good starting point, but are basic and superficial. Certainly, if an investigator

⁷⁰³ See note 706 and accompanying text.

⁷⁰⁴ OCR, Emergency Services memorandum, p. 2.

⁷⁰⁵ Ibid.

⁷⁰⁶ Ibid.

⁷⁰⁷ Ibid.

⁷⁰⁸ Ryan L. Everhart, comment, "New York Managed Care Legislation: A Substantive Response to Corporate Medicine or a Token Gesture to Ease Consumer Concerns?" *Buffalo Law Review*, vol. 46 (spring 1998), p. 531 (citing Vicki A. Baldassano, MCOs, Emergency Room Doctors at Odds over Coverage of Urgent Care," *Health Law Reporter* (BNA), vol. 4 (Oct. 12, 1995), p. 1546).

⁷⁰⁹ Ibid. (citing Christopher J. Young, comment, "Emergency! Says Who? Analysis of the Legal Issues Concerning Managed Care and Emergency Medical Services," *Journal of Contemporary Health Law and Policy*, vol. 13 (1997) pp. 553-54).

⁷¹⁰ Ibid.

were able to answer correctly and confidently the suggested questions, the investigation would have been adequate. However, the subchapter gives no guidance on how to derive the answers.⁷¹¹ For instance, in cases of patients whose symptoms are ambiguous, the effect of race or inability to pay on a medical professional's judgment may be more apparent. In such cases, pair comparisons would be helpful. In a pair comparison, the investigator would check into the treatment records of the particular triage nurse or doctor to see whether patients with similar symptoms were denied treatment. The suggested data sources should include Public Health Service physicians. An objective opinion would be critical in a paired comparison test.

Finally, the subchapter fails to integrate the substantive legal and evidentiary components of a case. For instance, although the subchapter recommends basic questions and suggests what forms of evidence to gather, it leaves up to investigators how to analyze the information that is collected. It fails to explain how the evidence relates to each issue of patient dumping. Hypothetical examples that demonstrate how to use the evidence would be helpful for investigators.

The antidumping instructions dated May 1988,⁷¹² by contrast, reach much further in explaining to the investigator the purpose of gathering specific information as well as how to utilize it in the investigation. In view of the lengthy policy guidance that already exists, a shorter guidance document, such as the subchapter described above, may be of little comparative value. However, given the reduction in prominence of the antidumping caseload after EMTALA, the decreased amount of guidance may not have a substantial deleterious impact.

Title IX: Rulemaking and Policy Development

OCR's title IX regulations prohibit discrimination on the basis of sex in admission to institutions of vocational education, professional education, graduate higher education, and public institutions of undergraduate higher education

(except for those that are traditionally single-sex institutions).⁷¹³ The title IX regulations have not been updated since they were issued originally by HEW in 1975. As with its title VI regulations, OCR's title IX regulations are essentially the same title IX regulations issued by DOE.⁷¹⁴ OCR, therefore, has not adapted its title IX regulations to the health care context. Consequently, nothing in the regulations or interpretive guidance contained in appendices to the regulations is specific or uniquely relevant to recipients providing medical and other forms of health care related educational services.

The title IX regulations give several specific examples as to what constitutes prohibited discrimination in admissions. These include:

- Giving preference to one student over another on the basis of sex (including admitting students based on separate ranked lists by sex).
- Placing numerical restrictions on the number of students of either sex who can be admitted.
- Using tests or other criteria for admission that have an "adverse effect" on the basis of sex, unless such test or criteria are shown to predict educational success and other neutral criteria are not available.⁷¹⁵

The title IX regulations require a certain minimum threshold of quality in the services, facilities, and resources used in that they must be comparable to the services, facilities, and resources provided to students of the other sex.⁷¹⁶ The regulations proscribe recipients from having admissions policies relating to marital or parental status that differ by sex, from discriminating in admissions based on pregnancy, from treating pregnancy-related disabilities differently from other temporary disabilities, and from making preadmission inquiries about applicants' marital status.⁷¹⁷ Finally, the regulations prohibit recipients from giving admissions preferences to applicants who have attended institutions that are predominantly of one sex, from discriminating

⁷¹¹ OCR staff have stated that they may incorporate more in-depth investigative guidance before finalizing the chapter. Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 1.

⁷¹² OCR, Instructions—Dumping Issues.

⁷¹³ 45 C.F.R. § 86.15(c), (d), (e) (1998).

⁷¹⁴ See 45 C.F.R. pt. 106 (1998).

⁷¹⁵ 45 C.F.R. § 86.21(b)(1)–(2) (1998).

⁷¹⁶ *Id.* § 86.33.

⁷¹⁷ *Id.* § 86.21(c)(1)–(4).

on the basis of sex in the recruitment of students, and from recruiting primarily at single-sex institutions.⁷¹⁸

The title IX regulations also prohibit discrimination on the basis of sex in education programs and related activities.⁷¹⁹ This prohibition applies to “any academic, extracurricular, research, occupational training, or other education program or activity” operated by a recipient.⁷²⁰ The regulations provide a number of specific examples of prohibited actions, and require recipients to ensure that discrimination does not occur in programs offered, but not operated by, the recipient. They address housing and physical education facilities, providing that separate housing and physical education facilities can be provided, but that housing for both sexes should be comparable.⁷²¹

Based on the language of the statute, the title IX regulations contain a blanket prohibition against employment discrimination based on sex by recipients of Federal financial assistance.⁷²² The regulations contain specific provisions clarifying the prohibition as it applies to employment criteria, recruitment, compensation, job classification and structure, fringe benefits, marital and parental status, advertising, preemployment inquiries, and sex as a bona fide occupational qualification.⁷²³

Adapting the regulations to address specific issues directly relating to health care, such as medical school admissions, would help to ensure that OCR’s title IX compliance requirements reflect the mission and responsibilities unique to HHS and its health care funding recipients, as opposed to those shared with the many kinds of educational funding recipients covered under the Department of Education’s title IX regulations. Updating and expanding the title IX regulations would be particularly timely at this juncture, because DOJ/CORS is currently working with several other Federal agencies to develop their first editions of title IX regulations.⁷²⁴ At a

minimum, the development of interpretive guidance to the regulations contained in a new appendix would help OCR greatly in providing further clarity and detail to issues that are relevant to recipients providing medical and other forms of health care related educational services.

OCR has not developed any policy guidance on title IX enforcement issues. Part of the reason appears to be OCR’s perception that violations of title IX by health care funding recipients are rare. A senior civil rights attorney in HHS’ Office of General Counsel has stated that he has seen very few title IX complaints in the 12 years he has been with the agency.⁷²⁵ However, because OCR does not focus its compliance reviews on title IX, it is impossible to know whether the lack of complaints indicates that there are no violations of the statute, or whether they simply have gone unreported.

Given that HHS/OCR shares responsibility for enforcing title IX with the Department of Education’s Office for Civil Rights, a memorandum of understanding between the two agencies would appear useful to both agencies in ensuring effective enforcement of title IX. No such document currently exists in final form.⁷²⁶ However, HHS/OCR is currently collaborating with DOEd/OCR and DOJ/CORS to develop an agreement that will address the issue of overlap in title IX enforcement.⁷²⁷ This project is part of a larger, renewed effort by DOJ/CORS to coordinate enforcement among the Federal agencies that have title IX authority.⁷²⁸ One of the results will be a series of delegation agreements that will “delineate the enforcement responsibilities of Federal agencies under title IX, including the responsibilities of HHS and DOEd.”⁷²⁹

⁷¹⁸ *Id.* §§ 86.22, 86.23.

⁷¹⁹ *See generally* 45 C.F.R. pt. 86.

⁷²⁰ *Id.* § 86.31(a).

⁷²¹ *Id.* §§ 86.32, 86.33.

⁷²² *Id.* § 86.51.

⁷²³ *Id.* §§ 86.52 – 86.61.

⁷²⁴ *See* Jeanette J. Lim, director, Program Legal Component, OCR, Department of Education, letter to Frederick D. Isler,

assistant staff director for Civil Rights Evaluation, Jan. 26, 1999 (re: coordination of title IX enforcement between HHS and DOEd), pp. 3–4 (hereafter cited as Lim letter); CORS interview, p. 4 (statement of Friedlander).

⁷²⁵ OGC interview, p. 17.

⁷²⁶ Thomas E. Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, Apr. 1, 1999 (re: coordination of title IX enforcement between HHS and DOEd) (hereafter cited as Perez letter); Lim letter, p. 1.

⁷²⁷ Perez letter, p. 1.

⁷²⁸ *See* Lim letter, pp. 3–4. *See also* CORS interview, p. 4 (statement of Friedlander).

⁷²⁹ *See* Perez letter, p. 1; Lim letter, pp. 3–4.

In addition, HHS/OCR has emphasized its commitment to effective communication between HHS/OCR and DOEd/OCR. According to the director of HHS/OCR, the two offices are in regular contact over a variety of civil rights issues that extend well beyond title IX enforcement.⁷³⁰ However, due to the dearth of policy development and enforcement activity on the part of HHS/OCR, no outer manifestations of this cooperative relationship exist with regard to title IX.

Title IX Compliance in Specific Contexts

Health Care Research

There are potential health care/medical related issues that may implicate title IX. For example, title IX covers students in universities that have medical schools and/or teaching hospitals receiving Federal funds.⁷³¹ A number of title IX compliance issues could arise in this context. For example, issues relating to the practice of using only males for medical research studies recently has received a great deal of attention and concern among scholars, the news media, Congress, and HHS itself.⁷³² One commentator has noted:

⁷³⁰ Perez letter, p. 1.

⁷³¹ See 45 C.F.R. §§ 86.1, 86.31(a).

⁷³² See Mastroianni, "HIV, Women, and Access to Clinical Trials," p. 167 (stating that "[t]here is a growing recognition that disease processes, the manifestations of disease, and physiological responses to treatment sometimes may differ in men and women. Thus, information from clinical studies that either exclude women or include them in numbers too small to provide meaningful information may be insufficient to extrapolate to health conditions and disease treatment in women." Ibid., p. 167; Rothenberg, "Gender Matters," p. 1201 (stating that "[t]he effects of exclusion from clinical research are far reaching. All women suffer the consequences of studies that include only men, or that include women, but do not adequately analyze any gender-related differences." Ibid., p. 1208); Fiscal Year 1999 Departments of Labor and Health and Human Services Appropriations: Hearings Before the Subcomm. On Labor, Health and Human Services, and Education of the Senate Comm on Appropriations, 105th Cong. (Apr. 1, 1998) (statement of Ruth L. Kirschstein, deputy director, National Institute of Health). Ms. Kirschstein spoke about HHS initiatives to ensure that women are represented in clinical research trials. She stated that "the Office of Research on Women's Health (ORWH) . . . strives to ensure that NIH supported research addresses health issues of concern to women, that women are appropriately included as subjects in research protocols and clinical trials, and that women are encouraged to pursue careers in medical research. Working from a comprehensive research agenda that approaches women's health across the life span, ORWH will use its budget to stimulate, initiate, and expand women's health research by supporting

[U]sing the categories of race and gender with an implicit assumption that "white" and "male" are the normative or standard-making categories for measuring health and determining health needs . . . leaves untouched the effects of using the white male as the standard for determining need. For example, when the gender question was asked, the risks for women of doing clinical studies on men suddenly became obvious. Aspirin, for example, had become a widely accepted prophylactic for coronary artery disease; however, because the risks and benefits were assessed in a trial group consisting almost entirely of men, the real risks and benefits for women remained unknown . . . The biases used to demonstrate the need for policy reform at the federal level have been many and varied. Research funding, as well as research methods, have disproportionately benefited men.⁷³³

At least one commentator has observed that title IX might provide the basis for a claim of sex discrimination by women excluded from clinical trials or other health care/medical research conducted at educational institutions receiving Federal funds.⁷³⁴ She has suggested that "[p]otential research participants excluded by reason of their gender might be entitled to relief under this provision, but would have to establish that they are 'persons' protected from discrimination under the Act and that their exclusion from research trials constituted 'discrimination'."⁷³⁵

Observations such as these from scholarly commentators indicate major concerns over the presence of significant barriers to women's participation in health care research studies. These barriers may constitute violations of title IX when the research is occurring in federally funded educational institutions. Whether and under what kinds of circumstances the failure to use women as subjects in such studies can amount to a violation of title IX is an issue OCR should address in a policy memorandum to regional office directors or other form of guidance.

The Commission found that some senior regional investigative staff actually were unaware that OCR had developed regulations under title IX and were generally unfamiliar with OCR's

research grants, RFAs, Program Announcements, and Research Enhancement." Ibid.).

⁷³³ Ikemoto, "The Fuzzy Logic of Race and Gender," pp. 803-04 (citations omitted).

⁷³⁴ See Bobinski, "Women and HIV," p. 22, n. 55.

⁷³⁵ Ibid. See also OGC interview, pp. 17-18.

enforcement responsibilities under title IX.⁷³⁶ In interviews with Commission staff, these regional staff members stated repeatedly and emphatically that they were not aware of regulatory guidance by OCR on title IX.⁷³⁷ This lack of awareness about a matter as fundamental to OCR's work as which statutes it has developed regulations on is a strong indicator of the need for policy and/or investigative guidance addressing OCR's title IX responsibilities.

Many recipients of HHS funding may also be unaware of their responsibilities under title IX, and many beneficiaries are probably not being informed of their rights. Therefore, the failure of some OCR regional staff to know that OCR has developed regulations on title IX indicates the need for a twofold response by OCR to address the problem: first, OCR must implement a plan to ensure that its entire staff is trained properly on *all* of the agency's enforcement responsibilities before it can expect staff to carry them out effectively; and, second, this problem clearly indicates the need for technical assistance, and outreach and education efforts to promote compliance and publicize the agency's title IX enforcement mandate.

Medical Study and Practice

The barriers women continue to face in gaining access to medical schools and medical practice add another dimension to the issue of title IX compliance among health care funding recipients, particularly medical schools and hospitals. Improvement in the quality of health care for female patients is one of the benefits that may result from stronger efforts to remove barriers to medical practice for women.

For example, one researcher has concluded that women are more likely to undergo screening with Pap smears and mammograms if they see female rather than male physicians.⁷³⁸ A commentator writing on research and women's health reported studies that have found female patients may be more likely to follow through in

obtaining tests suggested by female physicians because they are more comfortable discussing issues of concern with female physicians; and the longest office visits are between female physicians and female patients and the shortest are between male physicians and female patients.⁷³⁹ With these findings in hand, it seems logical that OCR and other government entities should work in partnership with medical schools and health care facilities to ensure that women doctors have equal opportunity to pursue careers in medicine in any field they choose. However, as one commentator has noted, "Physicians who are women or persons of color improve the availability and quality of health care, particularly for patients in those categories, but because of barriers to the medical academy and profession, women and persons of color are underrepresented among physicians."⁷⁴⁰

Among the most significant barriers are medical school programs that appear to be steering women medical students toward specialty fields associated with traditional feminine roles such as pediatrics and obstetrics.⁷⁴¹ As a result, women are clustered in specific areas of medicine and remain poorly represented in the field of medical research. One study has found that women physicians were clustered in five areas: internal medicine, pediatrics, family practice, obstetrics/gynecology and psychiatry.⁷⁴² This clustering phenomenon suggests limitations on women's opportunities in practicing medicine that are inconsistent with the objectives of title IX's nondiscrimination mandate.

As the agency tasked with ensuring compliance with title IX among HHS funding recipients, OCR's role in encouraging medical schools to address barriers to access and participation for women students must be a proactive one. OCR must develop both policy and technical assistance materials geared toward medical school recipients. Such documents should address strategies to ensure that barriers for women in medical school are removed to the greatest extent possible. These documents also should re-

⁷³⁶ Floyd Plymouth, Delores Braun, Gloria Silas-Webster, and Fay Dow, equal opportunity specialists, Region X, OCR, HHS, telephone interview, Feb. 2, 1999, p. 8 (hereafter cited as OCR Region X EOS interview).

⁷³⁷ OCR Region X EOS interview, p. 8.

⁷³⁸ Ikemoto, "The Fuzzy Logic of Race and Gender," p. 804, n. 18 (citing Nicole Lurie et al., "Preventive Care for Women," *New England Journal of Medicine*, vol. 329 (1993), p. 478).

⁷³⁹ Rothenberg, "Gender Matters," pp. 1212-13.

⁷⁴⁰ Ikemoto, "The Fuzzy Logic of Race and Gender," p. 804.

⁷⁴¹ See USCCR, *The Health Care Challenge*, vol. I, chap. 2.

⁷⁴² American Medical Association, Department of Data Survey and Planning, *Physician Characteristics and Distribution in the US, 1996-97* (Chicago, IL: American Medical Association, 1997), p. 14.

mind medical school recipients that any such efforts may be crucial to avoid non-compliance with title IX's mandate.

Overall Assessment

At least one policy guidance on title IX in the context of health care could be an effective mechanism for training OCR staff and educating funding recipients about what might constitute a violation of title IX and how compliance can be effected in specific circumstances. Such a policy guidance might describe the legislative history of the statute, its regulations, and any relevant legal cases or administrative proceedings. Such a guidance also could contain hypothetical examples of title IX compliance issues in the health care/medical context, perhaps addressing title IX violations present in medical school admissions and research programs, which would be useful to investigative staff.

Nondiscrimination Provisions in Block Grants: Rulemaking and Policy Development

While the Department of Health and Human Services has issued general departmental regulations implementing its block grant programs,⁷⁴³ OCR has not developed any regulations implementing the nondiscrimination provisions. According to a 1984 report by the General Accounting Office, this amounts to a failure to respond to the increased responsibility and broader discretion imposed upon State recipients by the block grant revolution.⁷⁴⁴ In January 1986, OCR issued a Notice of Proposed Rulemaking on Block Grant Programs that was never finalized.⁷⁴⁵ OCR proposed the rule as an addition to its title VI regulations. However, due

to a moratorium on rulemaking, OCR did not issue a final rule to codify these guidelines.⁷⁴⁶ Since 1986, OCR has not attempted to issue new regulations providing guidelines for block grant programs.

The proposed rule of 1986 would have given guidance as to the civil rights components of these three block grant statutes.⁷⁴⁷ For example, it would have explained that the sex nondiscrimination component proscribed discriminatory effects⁷⁴⁸ while the religious nondiscrimination element only proscribed intentional discrimination.⁷⁴⁹ Although regulations pertaining to all HHS block grant nondiscrimination provisions would be advisable, definitions of the independent sex and religious nondiscrimination provisions are critical. These two provisions extend civil rights protections beyond the scope of titles VI and IX, and to the extent they exceed this scope, there is no existing regulatory guidance.⁷⁵⁰ Part of the reason for OCR's lack of regulatory guidance in this area may be the malaise that has characterized the Federal Government's title VI rulemaking, a malaise that has been noted by at least one OCR official.⁷⁵¹ However, this period of inactivity may be coming to an end.⁷⁵²

Lack of Policy Development

As with title VI, Hill-Burton, and title IX, OCR has not focused a great deal of attention on policy development relating to the nondiscrimination provisions in block grants. OCR has not issued policy guidance relating to block grant issues since the 1980s. OCR relies mainly on guidance provided in a brief 1982 document on block grant procedures.⁷⁵³ These procedures are

⁷⁴³ 47 Fed. Reg. 29,472 (1982). These general regulations do not specifically address the nondiscrimination provisions contained in the block grant statutes. The supplementary information section accompanying the final rule does make reference to the nondiscrimination provisions of the block grant statutes, emphasizing that the block grant funds are subject to the requirements of titles VI, IX, section 504, and the Age Discrimination Act of 1973. *Id.* at 29,472, 29,480 (1982) ("Special Provisions: Nondiscrimination"). The final rule was announced 1 year after the passage of the Omnibus Reconciliation Act that created the seven block grant programs.

⁷⁴⁴ See U.S. General Accounting Office, *Federal Agencies' Block Grant Civil Rights Enforcement Efforts: Status Report*, Sept. 28, 1984, abstract, pp. iii, 22-28.

⁷⁴⁵ 51 Fed. Reg. 2,806 (1986).

⁷⁴⁶ According to officials at DOJ/CORS, the failure to get the regulations finalized was due to fears that the term relating to religious nondiscrimination was legally unsound. CORS interview, p. 2 (statement of Strojney).

⁷⁴⁷ See 51 Fed. Reg. 2,806 (proposed sections 92.6 and 92.7).

⁷⁴⁸ See 51 Fed. Reg. 2,806 (1986) (referring to proposed section 92.6).

⁷⁴⁹ *Id.* (referring to section 92.7).

⁷⁵⁰ Religion is not covered at all, and sex discrimination is only prohibited in the educational context.

⁷⁵¹ See Halverson interview, p. 5.

⁷⁵² See CORS interview, p. 5 (statement of Friedlander).

⁷⁵³ See Marcella Haynes, director, OCR Block Grant Task Force, memorandum to Betty Lou Dotson, director, OCR, HHS, Sept. 22, 1982 (re: block grant procedures), p. 2. In

based on OCR's interpretation of Federal and State responsibilities pursuant to the nondiscrimination provision in block grant programs.⁷⁵⁴

OCR's Region X has developed a very brief statement, *Policy on Investigative Complaints Based on Sex and Religion*.⁷⁵⁵ However, this document is inadequate as policy guidance. It provides very little information, no contextual discussion to clarify the coverage of the nondiscrimination provisions, and no illustrative examples of cases that have or might arise based on these provisions. It provides two statements as guidance for investigative staff. The first informs investigative staff that a complainant "must articulate a clear violation of the statute."⁷⁵⁶ What constitutes a violation of the statute is not delineated, especially the criteria to apply in assessing the presence of a violation.

The second statement in the Region X guidance notes that "[t]he office will investigate only those entities (program or activity) that receive federal funding from block grants which forbid discrimination based on sex or religion."⁷⁵⁷ Here a more comprehensive guidance could provide the contextual discussion referred to above. Specifically, it could address the definition, from a compliance perspective, of the terms "program or activity," and the different block grants programs and their recipients. In addition, it could provide examples of cases, actual or hypothetical, that illustrate the kinds of compliance issues that can arise and the appropriate standards to apply in determining whether there has been a violation based on sex or religion.

Another important issue that the guidance briefly mentions is the interaction between title IX, which also provides for nondiscrimination on the basis of sex, and the block grant provision statutes providing the same. The guidance states that "[a]s a first step in reviewing a complaint, the [investigative team] should determine whether or not the office has title IX (sex discrimination) jurisdiction in certain educational programs or programs with training components funded by the Department."⁷⁵⁸ This is a key issue and should be far more developed than it is in this document.

The only recent guidance disseminated to all OCR regional investigative staff on nondiscrimination requirements in block grant programs is contained in OCR's *Case Resolution Manual*. However, the manual's discussion on block grant statutes is brief, cursory, and contains little detail.⁷⁵⁹ Like the Region X document, as guidance for investigative staff, it has extremely limited value.

DOJ/CORS recently issued a comprehensive and informative memorandum providing guidance on the enforcement of the nondiscrimination provisions of the block grant statutes. This document, developed in response to the Commission's 1996 Federal title VI enforcement report applies to all Federal agencies having block grant programs, not just HHS. It can potentially provide assistance to OCR and other civil rights offices in developing and expanding their own civil rights enforcement programs in the block grant area.

terms of policy guidance to the States, a letter was sent to State Governors apprising them of their new responsibilities under the block grant program. See Betty Lou Dotson, director, OCR, HHS, Letter to Governor of each State, no date (re: notification of Governors' responsibilities pursuant to the nondiscrimination provisions of HHS block grant programs).

⁷⁵⁴ 51 Fed. Reg. 2,806.

⁷⁵⁵ HHS, OCR, Region X, "Policy on Investigating Complaints Based on Sex and Religion," undated.

⁷⁵⁶ *Ibid.*, p. 1.

⁷⁵⁷ *Ibid.*

⁷⁵⁸ *Ibid.*

⁷⁵⁹ See chap. 4, for further discussion of the *Case Resolution Manual*.

Chapter 4

Ensuring Civil Rights Compliance: OCR's Enforcement Efforts

*"Federal Agencies have a distinct responsibility to insure that discrimination in Federal assistance is abolished. Their ad hoc and often passive civil rights enforcement systems have not been sufficiently comprehensive either to measure or reduce inequitable distribution of Federal assistance. . . . Agency policies have thus permitted the perpetuation of more subtle forms of discrimination. . . ."*¹

The Office for Civil Rights (OCR) of the U.S. Department of Health and Human Services (HHS) conducts several key civil rights enforcement activities, including data collection and analysis; preaward and postaward compliance reviews, complaint investigations, and administrative and legal proceedings; oversight and monitoring of State recipients; and technical assistance and outreach and education activities. Each one of these activities plays a crucial role in OCR efforts to promote and ensure civil rights compliance. For example, OCR must rely on data reporting and analysis to determine the nature and extent of civil rights violations in conducting its compliance reviews and complaint investigations. An understanding of the uses of statistical and other data collected by OCR and an awareness of its importance in conducting civil rights enforcement activity is necessary to make an informed assessment of OCR's civil rights enforcement efforts. In particular, the effectiveness with which OCR uses data to conduct its compliance reviews is important because it is mainly through compliance reviews that OCR can uncover, remedy, and prevent new violations of civil rights laws.² OCR relies on compliance re-

views to ensure that recipients of HHS financial assistance practice nondiscrimination and remain in compliance with civil rights requirements, and to initiate enforcement actions against recipients who refuse to comply with civil rights requirements willingly.³

Another key factor in OCR's efforts to enforce civil rights laws is the agency's investigation of complaints alleging discrimination by recipients of HHS funding. OCR conducts complaint processing operations to investigate allegations of discrimination by health care facilities receiving Federal assistance. These operations are essential to the productivity and effectiveness of the agency in meeting its mandate to enforce civil rights laws. As with its compliance review findings, OCR initiates enforcement actions against recipients who refuse to comply with civil rights requirements willingly.

OCR's oversight and monitoring of continuing State programs is another key element of OCR's efforts to ensure compliance among HHS funding recipients. In many ways, the agency's oversight and monitoring activities of State recipients present a synthesis of all the efforts OCR undertakes in meeting its civil rights enforcement responsibilities. This is true in that such oversight and monitoring activity requires data analysis and reporting requirements, and involves compliance review and complaint investigation activity.

Technical assistance and outreach and education activities are other important means that OCR uses to help ensure that HHS recipients are complying with their civil rights obligations. Through technical assistance and outreach and education efforts, OCR can build understanding and awareness among recipients about the re-

¹ U.S. Commission on Civil Rights (USCCR), *To Know or Not to Know: Collection and Use of Racial and Ethnic Data in Federal Assistance Programs*, February 1973, p. 1 (hereafter cited as USCCR, *Collection and Use of Data*).

² See generally USCCR, *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*,

June 1996, chap. 5 (hereafter cited as USCCR, *Federal Title VI Enforcement*).

³ See generally *ibid.*, chap. 5.

sponsibilities they have under Federal civil rights laws. Importantly, technical assistance, outreach, and education are means for OCR to ensure that beneficiaries of Federal funds are fully aware of their rights under Federal laws and can act appropriately to protect these rights.

Because each of these activities plays a key role in helping OCR to meet its goal of rooting out discrimination in health care facilities or organizations receiving Federal funding, the level of quality OCR achieves in conducting these activities can have a significant effect on whether or not the agency will be effective in ensuring nondiscrimination. An examination of each of these individual elements shows the areas where HHS is failing to meet its implementation and enforcement objectives.

The U.S. Commission on Civil Rights evaluated OCR's enforcement activities based on the objectives for ensuring civil rights compliance that OCR itself has advanced. In 1996 OCR stated that it intended to place its "primary emphasis" in conducting its compliance activities on "effective change."⁴ According to OCR, this "effective change" would be based on principles of government reinvention; case prioritization; and creativity, which, in turn, would enable OCR to focus more of its resources on several key objectives, including finding violations, securing systemic compliance from recipients of HHS assistance (or other covered entities), and taking forceful corrective actions where necessary.⁵ Importantly, in identifying these objectives OCR added "we must not close our eyes when compliance issues are there."⁶ The Commission agrees with OCR that these objectives are appropriate means of ensuring compliance. In fact, the Commission's main purpose in describing and evaluating OCR's implementation and enforcement efforts is to assess the agency's efforts in meeting its objectives. The extent to which OCR has been "closing its eyes" to compliance issues is an important focus of the Commission's review of OCR's implementation and enforcement activities because the Commission seeks to assist OCR in fully realizing its objec-

tives. In particular, the Commission, through observation and analysis of OCR's enforcement planning and procedures, seeks to identify areas where OCR currently is failing to provide vigorous and effective civil rights enforcement.

A comparison between OCR's stated objectives in its planning and procedural guidance documents and the agency's actual performance, as observed in OCR's statistical and narrative reports; OCR's letters of findings, and other case closure documents; and the statements of recipients who have been the subject of OCR complaint investigations or compliance reviews, reveals several significant problems in OCR's civil rights compliance and enforcement operations. For example, as the discussion below indicates, OCR has not implemented many of the priorities it has identified in its enforcement planning documents. Moreover, OCR's procedural guidance to investigative staff is not detailed or thorough enough to provide effective guidance to staff. In addition, OCR's letters of finding and statements of recipients suggest serious problems with OCR's investigative techniques such that OCR's ability to uncover compliance violations through systemic compliance reviews and complaint investigations is seriously compromised.

What is more troubling is that problems identified by the Commission in its current study are the very same problems that appear to have plagued the agency for many years. The report of a congressional investigation completed in 1987 highlights the long history of weak enforcement efforts that has characterized HHS' OCR since its inception in 1980. Some of the more significant problems identified in this investigation were presented in testimony before the House Committee on Government Operations. The report stated that "[t]estimony provided to the subcommittee noted that OCR repeatedly demonstrates its reluctance to process complaints and compliance reviews with the care and consideration for the law, the recipient and the beneficiaries that the committee expects."⁷ In her statement before the committee, Sylvia Drew Ivie, then director of the National Health Law Program, observed that "[m]any OCR administrative complaint decisions indicate superficial investigations and demonstrate that many

⁴ U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), *Case Resolution Manual*, June 21, 1996, "Introduction" (hereafter cited as OCR, CRM).

⁵ *Ibid.*, "Introduction."

⁶ *Ibid.*

⁷ H.R. REP. NO. 100-56, at 16 (1987).

times OCR fails to follow its own written standards and policies."⁸ Ms. Ivie also made a powerful statement before the committee that resonates more than 12 years later in the Commission's findings regarding OCR's current civil rights enforcement efforts to ensure compliance among HHS funding recipients. Ms. Ivie stated:

OCR's resolution of complaints is illusory since HHS reviews accept a hospital's written policy as determinative of whether a complainant's allegations were meritable rather than investigating what the hospital's *actual* practice was at the time in question. In many instances, OCR accepts a physician's or a nurse's opinion that emergency care was not needed without independent review of the patient's assessment or diagnosis. Repeatedly OCR fails to apply its own definition of emergency services and its policies for wrongful denial. Complaint determinations from different regional offices are inconsistent and confusing . . . Thus it is very difficult to obtain relief for wrongful denials to necessary emergency care . . . Where violations are cited . . . the hospital is just required to implement a "written" policy which will "supposedly" prevent future violations. It is our understanding that OCR does not follow through to see whether hospitals have actually implemented the policies mandated.⁹

Each of the observations Ms. Ivie made in her statement reflects major concerns identified by the Commission in its 1996 review of HHS operations¹⁰ and in this current study.

Taken together, the 1987 congressional report on OCR's operations, the Commission's 1996 report, and the Commission's current findings indicate that OCR's numerous deficiencies reflect a pervasively lackadaisical approach to conducting civil rights enforcement activities that has become firmly entrenched over a long period of time and has remained resistant to political and other forms of change. The Commission's assessment of OCR's civil rights enforcement activities focuses on its efforts to conduct

thorough data analysis and to implement an effective enforcement process, from assurances and preaward reviews to compliance reviews, complaint investigations, and case closures, reached both through administrative and legal means.

Data Analysis and Reporting Requirements

*"We cannot know the full extent of race- and ethnic-based barriers to care without collecting, compiling, and publishing provider-specific information, including race- and ethnic-specific data on enrollment, utilization, and treatment. Truly universal access depends on the elimination of all barriers to health care. Achieving that access depends on effective enforcement of civil rights; and that enforcement, in turn, is dependent on the existence and availability of data about the treatment of protected groups."*¹¹

Through its data collection and analysis efforts, HHS/OCR can obtain statistical and other information valuable to evaluating potential civil rights violations. Unfortunately, OCR currently does not have adequate access to appropriate data. As described by an observer:

Title VI certification and compliance involves essentially the completion and filing of a form. There are no standard forms or procedures adopted by the state agencies responsible for title VI certification. No analysis or summary reports are routinely completed from these efforts. While OCR conducts its own compliance reviews of facilities, budget limitations make possible to do only a few each year in each region. Yet even for these limited federal compliance reviews, investigators have no data resources other than census figures. In the age of the information superhighway, investigators must often rely on hand tabulation from facility records.¹²

The importance of appropriate data as a means of facilitating effective civil rights enforcement efforts cannot be overstated. Without adequate data, it is impossible to show disparities based on race in health care access and

⁸ *Id.* (citing Hearings before a Subcommittee of the Committee on Government Operations, House of Representatives, "Oversight of the Office for Civil Rights at the Department of Health and Human Services," Aug. 6 and 7, 1986).

⁹ H.R. REP. NO. 100-56, at 18 (1987) (citing Hearings before a Subcommittee of the Committee on Government Operations, House of Representatives, "Oversight of the Office for Civil Rights at the Department of Health and Human Services," Aug. 6 and 7, 1986) (emphasis added).

¹⁰ See generally USCCR, *Federal Title VI Enforcement*.

¹¹ Sydney Dean Watson, "Minority Access and Health Reform: A Civil Right to Health Care," *Journal of Law, Medicine, and Ethics*, vol. 22, no. 2 (summer 1994), p. 133.

¹² David Barton Smith, *Health Care Divided: Race and Healing a Nation* (Ann Arbor, MI: The University of Michigan Press, 1999), p. 322.

treatment, much less the connection between such disparities and specific practices of health care funding recipients. One commentator has noted that the Federal Government already collects a significant amount of data about minority participation in federally funded education and private employment, and that similar information about minority health care use is needed just as much.¹³ In particular, health care providers and insurers need to gather and provide HHS/OCR with data on enrollment, utilization, and treatment of racial and ethnic minorities and women. Moreover, these recipients should collect, compile, and publish provider-specific information.¹⁴

OCR has a limited data collection and analysis system; other than the Hill-Burton program's Community Service Assurance Reporting System, OCR does not regularly or systematically collect data from its recipients.¹⁵ During pre-grant reviews of facilities applying for Medicare certification, OCR regional offices collect information on the racial/ethnic composition of program participants, but do not collect data on their sex.¹⁶ Data requests made in conjunction with compliance reviews are limited in scope and tailored to the issues involved in the review.¹⁷

¹³ Ibid.

¹⁴ Ibid. The Institute of Medicine's Committee on Monitoring Access to Personal Health Services has recommended the establishment of one agency that would be responsible for the centralized collection, analysis, improvement, and dissemination of the Nation's data on access to health care. See Michael Millman, ed., *Access to Health Care in America* (Washington DC, National Academy Press, 1993), pp. 138-39. The Commission concurs with this recommendation. For further recommendations regarding data collection, see chap. 4.

¹⁵ USCCR, *Federal Title VI Enforcement*, p. 233. See also Steve Melov, director, Management Information and Analysis Division, and Pamela Malester, deputy director, Quality Assurance and Control Division, Office of Management Planning and Evaluation, OCR, HHS, interview in Washington, DC, Nov. 20, 1998, p. 6 (statement of Melov) (hereafter cited as OMPE interview); Caroline Chang, regional manager, Region I, OCR, HHS, telephone interview, Feb. 17, 1999, p. 11 (hereafter cited as Chang interview); Marie Chretien, regional manager, Region IV, OCR, HHS, telephone interview, Feb. 9, 1999, p. 12 (hereafter cited as Chretien interview); John Halverson, regional manager, Region VII, OCR, HHS, telephone interview, Feb. 9, 1999, p. 8 (hereafter cited as Halverson interview).

¹⁶ OMPE interview, p. 7 (statement of Melov).

¹⁷ Chang interview, p. 11; Chretien interview, p. 12; Arnold Loperena, Patricia Holub, and Victor Hidalgo, equal opportunity specialists, Region II, OCR, HHS, telephone inter-

Similarly, during the course of a complaint investigation, OCR collects whatever data are necessary to address the issues raised in an allegation, in order to make a finding.¹⁸ Thus, OCR's collection of data is a random process.

For more than 30 years, the Commission has commented on the absence of adequate data collection in HHS' enforcement activities, yet little has been done to address this deficiency.¹⁹ The Commission has long supported the systematic collection of racial and ethnic data.²⁰ The Commission's *Compliance Officer's Manual* stresses that data collection is essential because racial, ethnic, and gender disparities in access to programs and patterns of discrimination may be revealed by statistical analyses of records maintained by recipients of Federal funds.²¹ Data collection is the primary means by which agencies can monitor whether their program funds are reaching the intended beneficiaries and communities that need assistance from HHS. When HHS and its recipients can appropriately assess the reach of its program funds, they are in a better position to assess whether corrective action is necessary to ensure nondiscrimination. This information may be used in all stages of the compliance process and may assist in developing case analysis.²²

view, Feb. 3, 1999, p. 4 (hereafter cited as OCR Region II EOS interview); Andrea Oliver, Jean Lovato, Doris Genko, equal opportunity specialists, Region VIII, OCR, HHS, telephone interview, Feb. 9, 1999, pp. 3-4 (hereafter cited as OCR Region VIII EOS interview).

¹⁸ OMPE interview, p. 7 (statement of Melov).

¹⁹ See vol. II, chap. 1. See, e.g., USCCR, *HEW and Title VI: A Report on the Development of the Organization, Policies, and Compliance Procedures of the Department of Health, Education, and Welfare Under Title VI of the Civil Rights Act of 1964*, clearinghouse publication no. 22, 1970, p. 72; USCCR, *The Federal Civil Rights Enforcement Effort: One Year Later*, November 1971, pp. 136-40; USCCR, *The Federal Civil Rights Enforcement Effort—1974*, November 1975, pp. 152-79, 190-97; USCCR, *Federal Title VI Enforcement*, pp. 245-47.

²⁰ See generally USCCR, *Collection and Use of Data*.

²¹ USCCR, *Compliance Officer's Manual: A Handbook of Compliance Procedures Under Title VI of the Civil Rights Act of 1964*, October 1966, p. 10.

²² USCCR, *Federal Title VI Enforcement*, p. 181.

Requirements for Federal Agencies to Collect and Maintain Data

DOJ's coordination regulations require Federal agencies to implement a system of data and information collection within federally assisted programs, "to permit effective enforcement of title VI."²³ The regulations indicate that agencies should collect data on the way in which services will be provided by the program; the racial and ethnic composition of the eligible population; employment in the program, including the use of bilingual employees to serve limited-English-proficient (LEP) applicants and recipients; the effect the location or any relocation of the program has on racial and ethnic groups; and the racial and ethnic composition of planning or advisory bodies that are an integral part of the program.²⁴ In all cases, Federal agencies are required to collect from applicants information on any lawsuits alleging discrimination filed against them, a description of any pending applications for assistance from other Federal agencies, a description of any civil rights compliance reviews the applicant has undergone, an assurance that the applicant will collect and maintain required data, and information on whether the applicant has been found in non-compliance with civil rights laws.²⁵

Currently, HHS regulations require recipients to maintain data and authorize OCR to collect such information as necessary to determine compliance.²⁶ HHS title VI regulations indicate that each recipient of HHS funds shall keep records and submit complete and accurate compliance reports to HHS when requested so that the Department may determine if the recipient is complying with title VI.²⁷ For example, recipients should have available for the Department racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in federally assisted programs. In addition, each recipient "shall permit access (during normal business hours) by the responsible Department official or his designee during normal business hours to such of its

books, records, accounts, and other sources of information. . . ."²⁸ According to OCR staff, if funding recipients do not provide the requested data in a complete, timely, and accurate manner, OCR can initiate administrative or legal enforcement proceedings.²⁹

Among the responsibilities assigned to State recipients administering federally assisted programs under the DOJ regulations is "the maintenance of records necessary to permit federal officials to determine the title VI compliance of state agencies and sub-recipient."³⁰ The States must make records accessible to HHS, so that HHS is able to determine whether the States and their subrecipients are in compliance with title VI.³¹ The HHS title VI regulations also state that the subrecipient must submit compliance reports to the primary recipient to enable it to carry out its title VI obligations.³² A 1999 DOJ policy guidance document indicated that Federal agencies should require States to maintain readily accessible data that identify the States' respective subrecipients. DOJ also indicated that Federal agencies should discuss with State

²⁸ *Id.* § 80.6(c).

²⁹ Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy director, Valita Shepperd, deputy director, Program Development and Training Division; Ronald Copeland, associate deputy director; Johnny Nelson, deputy director, Voluntary Compliance and Outreach Division; Toni Baker, director, Investigations Division; Office of Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13 and 18, 1998, pp. 49-50 (statement of Mackey) (hereafter cited as OPO interview); OMPE interview, p. 8 (statement of Melov). See OCR, CRM, pp. 34-35. During the 1960s, HHS suspended and terminated assistance to hospitals that continued to maintain segregated facilities. More recently, OCR has used its enforcement authority in cases where there has been failure to respond or resistance by an entity that argues that it does not have to provide the requested data. However, there has not been a suspension or termination of grant funds in HHS in recent years. OMPE interview, p. 8 (statement of Melov); George Lyon, associate general counsel, Civil Rights Division, Office of General Counsel, HHS, interview in Washington, DC, Dec. 22, 1998, p. 7 (hereafter cited as OGC interview).

³⁰ 28 C.F.R. § 42.410 (1998). See also USCCR, *Federal Title VI Enforcement*, p. 179.

³¹ *Id.* § 42.410. See also USCCR, *Federal Title VI Enforcement*, p. 178.

³² *Id.* § 80.6(b).

²³ 28 C.F.R. § 42.406(a) (1998).

²⁴ *Id.* § 42.406(b).

²⁵ *Id.* § 42.406(d)-(e).

²⁶ 45 C.F.R. § 80.6(b) (1998).

²⁷ *Id.* § 80.6(b).

agencies the specific types of, and methods for, data collection.³³

In 1996 the Commission reported in its title VI report that HHS, similar to other Federal agencies, did not monitor its State recipients' title VI compliance and enforcement activities by reviewing the racial/ethnic data that is supposed to be collected by State agencies.³⁴ Sporadic oversight by OCR of its State recipients, with respect to assessing their compliance with title VI and procedures to ensure subrecipients' compliance, continues.³⁵ For instance, Region VII³⁶ does not send to State recipients on a systematic basis a data collection instrument to assess their own and their subrecipients' compliance with civil rights statutes. Similarly, Region VIII³⁷ equal opportunity specialists (EOS) reported that State agencies have no reporting requirements.³⁸ The regional manager in Region II³⁹ also reported that racial/ethnic and gender data are not collected from State recipients "as frequently as should be the case."⁴⁰ The Region III⁴¹ manager stated that he does not consider the

gender and racial/ethnic data collected by the States reliable, and so Region III does not analyze it.⁴²

HHS' data collection regulations were at issue in *Madison Hughes v. Shalala*⁴³ because the HHS title VI regulations do not require recipients to provide reports until HHS determines them to be necessary and prescribes their form and content, data collection is thereby a discretionary rather than mandatory activity and not subject to judicial review.⁴⁴ In this case, the Department's position that it collects sufficient data it needs to enforce title VI was upheld at both the district and appeals court levels.⁴⁵ The circuit court judges argued that HHS' regulation does not provide a standard of data collection, since it authorizes HHS to request and receive from recipients the particular types of information that the Department deems necessary.⁴⁶ The appellate court ruled that HHS is entitled to require different types of racial data, depending on the type of review or investigation or other individual circumstances.⁴⁷ Because the regulation establishes no "substantive priorities," crite-

³³ Bill Lann Lee, Acting Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, memorandum to executive agency civil rights directors, Jan. 28, 1999 (re: enforcement of title VI of the Civil Rights Act of 1964 and related statutes in block grant-type programs) (hereafter cited as DOJ, Title VI Policy Guidance).

³⁴ USCCR, *Federal Title VI Enforcement*, p. 3.

³⁵ See Marcella Haynes, director, Policy and Special Projects Staff, and Kathleen O'Brien, special assistant, OCR, HHS, interview in Washington, DC, Nov. 16, 1998, pp. 19-20 (statement of Haynes) (hereafter cited as PSPS interview); Marcella Haynes, director, Policy and Special Projects Staff, OCR, HHS, telephone interview, Dec. 9, 1998, p. 6 (hereafter cited as Haynes interview); Peter Kemp, Jan Ro-Trock, and Maria Smith, equal opportunity specialists/investigators, Region VII, OCR, HHS, telephone interview, Feb. 8, 1999, p. 8 (statement of Kemp) (hereafter cited as OCR Region VII EOS interview). See below for a discussion of OCR's efforts to monitor State agencies.

³⁶ Region VII covers Iowa, Kansas, Missouri, and Nebraska.

³⁷ Region VIII covers Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming.

³⁸ OCR Region VII EOS interview, p. 8; OCR Region VIII EOS interview, p. 9

³⁹ Region II covers New Jersey, New York, Puerto Rico, and the Virgin Islands.

⁴⁰ Michael Carter, regional manager, Region II, OCR, HHS, telephone interview, Feb. 2, 1999, p. 8 (hereafter cited as Carter interview).

⁴¹ Region III covers Delaware, the District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia.

⁴² Paul Cushing, regional manager, Region III, OCR, HHS, telephone interview, Feb. 23, 1999, p. 9 (hereafter cited as Cushing interview).

⁴³ 80 F.3d 1121 (6th Cir. 1996).

⁴⁴ *Id.* at 1128. In 1993 a lawsuit was brought against HHS/OCR by an African American and the Tennessee Interfaith Coalitions for Justice in Health Care. *Id.* at 1123. The plaintiffs were seeking to compel HHS "to collect data and information from recipients of federal assistance sufficient to permit effective enforcement of title VI." *Id.* The plaintiffs argued that HHS was not producing routine reports on the ethnic distribution of recipients by health care providers. *Id.* The litigation sought to have HCFA collect race/ethnicity data on every claim made by a medical facility/institution with respect to medicare patients. See Gordon Bonnyman, managing attorney, Tennessee Justice Center, telephone interview, Feb. 4, 1999, pp. 2-4 (hereafter cited as Bonnyman interview). See also USCCR, *Federal Title VI Enforcement*, p. 234; John Van Walker, senior advisor for technology to the chief information officer, Office of Information Services, Health Care Financing Administration, HHS, telephone interview, Dec. 30, 1998, p. 2 (hereafter cited as Van Walker interview); OPO interview, p. 51 (statement of O'Brien). The case was dismissed for lack of subject matter jurisdiction in 1994, and the dismissal was affirmed by the United States Court of Appeals for the Sixth Circuit in 1996, 80 F.3d at 1123, 1131.

⁴⁵ 80 F.3d at 1131; OMPE interview, p. 10 (statement of Melov).

⁴⁶ 80 F.3d at 1128.

⁴⁷ *Id.*

ria, or meaningful standards to use in assessing the sufficiency of HHS' data collection efforts for title VI enforcement, the court ruled that it must "defer to the broad discretionary judgment granted to HHS in how best to implement title VI."⁴⁸

The court acknowledged that title VI does impose a duty upon HHS to ensure compliance of each recipient of Federal funds. However, according to the court, data collection is only one of a variety of means through which HHS can accomplish this responsibility.⁴⁹ Overall, the court concluded that HHS' compliance information regulation requires HHS to collect data and information from recipients of HHS funds sufficient to permit the effective enforcement of title VI.⁵⁰ Similarly, OCR interprets its regulations such that HHS' applicants for grants and contracts are required to provide no further data (to substantiate their compliance with civil rights statutes) beyond submitting their assurance of compliance forms.⁵¹ Thus, HHS requires very limited data collection and maintenance activities.

Without more information, OCR's overall data analysis is too weak to assist the agency in carrying out its enforcement responsibilities. The ineffective nature of OCR's data analysis component in enforcing civil rights statutes illustrates a larger failure on the part of HHS. Put simply, in fulfilling its legal obligation to ensure compliance and prevent unlawful discrimination from occurring before it issues billions of dollars in Federal funds that affect the lives of millions of Americans, HHS must recognize fully the potentially "life and death" nature of the civil rights compliance issues that can arise in the health care context. Viewed in this light, it becomes apparent that HHS must establish a commitment to ensuring civil rights compliance

that is reflected in all of its efforts. Despite the *Madison-Hughes*' court's finding that data collection is only one of a number of means to help ensure civil rights compliance, OCR's current data analysis is insufficient to ensure compliance with the civil rights laws HHS has a mandate to enforce.

HHS Survey of Non-Hill-Burton Hospitals

In April 1996, OCR surveyed a random sample of 380 of the Nation's approximately 2,300 non-Hill-Burton hospitals (i.e., facilities that never received any Federal financial assistance under title VI and/or title XVI of the Public Health Service/Hill-Burton Act) to assess their compliance with title VI and section 504.⁵² All hospitals surveyed were recipients of medicare and/or medicaid funds (i.e., forms of Federal financial assistance) and were thereby obligated to admit and serve clients without regard to race, color, or national origin.⁵³ The director of OCR informed the surveyed hospitals that HHS' regulations implementing title VI of the Civil Rights Act required recipients to furnish to HHS racial/ethnic data on minority participation to assist HHS in its title VI compliance enforcement efforts.⁵⁴ The non-Hill-Burton facilities were asked to estimate, for instance, racial/ethnic minorities' percentage share of individuals who reside in the hospitals' primary service/geographic area, as well as provide data on the racial/ethnic composition and method of payment of inpatient admissions and emergency room service recipients.⁵⁵

Approximately 295 hospitals responded to OCR's civil rights compliance survey.⁵⁶ Preliminary results of the survey showed that 16 percent of non-Hill-Burton hospitals reported inpa-

⁴⁸ *Id.* at 1129.

⁴⁹ *Id.*

⁵⁰ *Id.* at 1131.

⁵¹ OPO interview, p. 26 (statement of Mackey). According to the deputy to OCR's associate deputy director, "[HHS] recipients are supposed to assure that they will comply with the civil rights laws. Signing the assurance of compliance is technically all that they have to do in terms of a preaward. They do not have to do anything more beyond that." *Ibid.*, pp. 26-27. "With respect to most of the grants and contracts, the [assurance of compliance] form has to be signed. That is all." *Ibid.*, p. 27. See discussion of assurances below.

⁵² OMPE interview, p. 11 (statement of Melov); Dennis Hayashi, director, OCR, memorandum to OPDIV and STAFF heads, Jan. 22, 1998 (re: civil rights compliance reports), p. 1 (hereafter cited as OCR, Hospital Memo).

⁵³ Dennis Hayashi, director, OCR, letter to Administrators of non-Hill-Burton hospitals, April 1996 (re: compliance with title VI of the Civil Rights Act of 1964) (hereafter cited as OCR, Letter to Non-Hill-Burton Hospitals); 42 U.S.C. § 2000d (1988).

⁵⁴ OCR, Letter to Non-Hill-Burton Hospitals.

⁵⁵ OMPE interview, pp. 8, 11 (statement of Melov); OMB no. 0990-0209 (Triennial V).

⁵⁶ *Ibid.*, p. 11 (statement of Melov).

tient data reflecting potential underservice to minorities in comparison with service area census data.⁵⁷ Approximately 11 percent of responding facilities in which 5 percent or more of the inpatients were Hispanic revealed potential compliance problems in the provision of services to LEP populations.⁵⁸ More than 40 percent of minorities served in the respondent non-Hill-Burton hospitals nationwide obtained services in hospitals that had a more than 50 percent minority inpatient census.⁵⁹ OCR appended these results with a statement declaring that none of the data in the analyses can be used to make any "legal presumption that any institution is in violation of civil rights laws."⁶⁰ OCR intended to use the information obtained from this survey as an "initial, but significant step in ensuring compliance with civil rights laws."⁶¹

Hill-Burton Community Service Assurance Reporting Requirements

Under the Hill-Burton Act,⁶² facilities that received funds under this law must comply with a community service assurance provision that states that facilities must make services available to all persons in its service area "without discrimination on the ground of race, color, national origin, creed, or any other ground unrelated to an individual's need for the service in the facility."⁶³ Currently, Hill-Burton data are collected every 3 years on Hill-Burton community service assurance forms (CSAs) from 3,500 hospitals, 500 nursing homes, and 1,100 other types of services providers, such as public health centers, medical laboratories, clinics, and reha-

bilitation centers.⁶⁴ The form asks recipients for information that is relevant to assessing their compliance with title VI, such as the number of inpatients admitted and their method of payment by race and ethnicity; the number of emergency room patients and their method of payment by race/ethnicity; as well as information on the accessibility of services to persons with limited English proficiency. The form also asks recipients to estimate the minority proportion of its locality but not to stratify this information by race/ethnicity.⁶⁵ From this information, OCR can assess the number of minority patients being treated at a facility, the proportion of minority patients being transferred to other facilities, and the number of medicaid patients being served.

Preliminary results of the most recent Hill-Burton survey, conducted in 1996, indicated that 12–13 percent of Hill-Burton hospitals reported inpatient data reflecting potential underservice to minorities (i.e., potential noncompliance with title VI or the community service assurance provision of the Hill-Burton Act) in comparison with service area census data.⁶⁶ Results were similar to OCR's 1996 survey of non-Hill-Burton facilities: almost 11 percent of responding facilities revealed potential compliance problems in the provision of services to LEP patients.⁶⁷ Approximately 42 percent of minorities served in the respondent Hill-Burton hospitals nationwide obtained services in hospitals that served primarily minority inpatients. These results were comparable to the data reported in earlier Hill-Burton reporting cycles.⁶⁸ Based on their compliance reviews and outreach activities conducted at health care facilities as a result of the Hill-Burton survey, OCR concluded that some

⁵⁷ OCR, Hospital Memo, p. 3. OCR used chi-square analysis to identify potential under- or overservice to minorities, by comparing reported racial/ethnic data with census data for a given hospital's service area. *Ibid.*

⁵⁸ *Ibid.*, p. 4.

⁵⁹ *Ibid.*

⁶⁰ *Ibid.*

⁶¹ *Ibid.*

⁶² Pub. L. No. 79-725, 60 Stat. 1040 (1946) (codified as amended at 42 U.S.C. §§ 291-291-o (1994)) (enacting title VI of the Public Health Service Act), Pub. L. No. 93-641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q-300t (1994)) (enacting title XVI of the Public Health Service Act).

⁶³ 42 C.F.R. § 124.603(a) (1998).

⁶⁴ Marcella Haynes, director, Policy and Special Projects Staff, OCR, HHS, letter to Frederick D. Isler, deputy assistant staff director, Office for Civil Rights Evaluation, USCCR, Apr. 6, 1994, p. 2 (hereafter cited as Haynes letter); OPO interview, p. 61 (statement of O'Brien). *See also* 42 C.F.R. §124.605(a) (1998).

⁶⁵ USCCR, *Federal Title VI Enforcement*, p. 233.

⁶⁶ OCR, Hospital Memo, p. 3.

⁶⁷ *Ibid.*, p. 4.

⁶⁸ *Ibid.* OCR stresses that a hospital reporting that it has more than 50 percent minority inpatient census does not indicate that this percentage has resulted from other hospitals' discriminatory practices (e.g., medical redlining, steering). Rather, geographic, transportation, residential patterns, and other demographic characteristics may explain such concentrations. *Ibid.*

Hill-Burton facilities "have forgotten that they have a continuing responsibility to provide services to the community."⁶⁹ However, OCR has not found that facilities are not providing services.⁷⁰

OCR's Strategies to Analyze CSA Reports

HHS' OCR's Office of Program Operations (OPO) is responsible for keeping track of OCR regional offices' activities with respect to the Hill-Burton program and maintains data collected by OCR during complaint investigations.⁷¹ Headquarters forwards the CSAs to the appropriate regional offices so that they can identify facilities for compliance reviews to target for additional information.⁷² In the regional offices' annual operating plans, the regions specify the Hill-Burton facilities that they have identified for onsite review or to provide technical assistance, outreach, and education.⁷³ The CSA is not intended to provide all of the information needed to determine if a Hill-Burton facility is in compliance with civil rights statutes or the community services assurance provision.⁷⁴ Rather, it is only a targeting instrument that can alert OCR to obtain additional information (e.g., through desk audits or onsite compliance reviews) on the particular Hill-Burton facilities whose CSA reports reveal potential compliance problems.⁷⁵

Using statistical tests, OCR has compared the racial/ethnic composition of inpatient admissions and emergency service recipients with the racial/ethnic composition of the facility service

area.⁷⁶ The analyses reveal whether facilities serve and admit a disproportionate number of individuals from various racial/ethnic groups. This information is then used to determine which facilities should be identified for compliance reviews. However, staff of OCR's Office of Management, Planning, and Evaluation (OMPE) claim that using CSA reports to determine which facilities will undergo a compliance review is part analysis and part art, and probably more art than science.⁷⁷ OCR staff are aware that because Hill-Burton facilities self-identify their respective service areas, some of the facilities have overestimated the size of their surrounding service areas, which has resulted in inaccurate analyses to determine if racial/ethnic minorities are served disproportionately.⁷⁸

According to OMPE staff, estimating the total number of Hill-Burton facilities that received compliance reviews between 1980 and the present is not possible.⁷⁹ National data are not available before 1984, or for 1995 and 1996.⁸⁰ Overall, based on available data, between 1984 and 1994, and 1997 to 1998, OCR conducted 1,302 compliance reviews on 1,099 Hill-Burton facilities. During the two time periods, 203 facilities (161 nursing homes and 42 other health facilities) had more than one review.⁸¹ OCR retains data only on the Hill-Burton facilities that actually had compliance reviews—not on all the facilities identified for a potential review. The stated reason for this decision is that OCR may plan to conduct a compliance review on a facility identified (via the data analysis) as serving minority groups on a disproportionate basis, but the onsite review may not actually occur.⁸²

⁶⁹ OMPE interview, p. 10 (statement of Melov).

⁷⁰ Ibid.

⁷¹ Kathleen O'Brien, special assistant to director and Patricia Mackey, deputy to associate deputy director, Office for Program Operations, OCR, HHS, interview in Washington, DC, Oct. 16, 1998, p. 6 (statement of O'Brien) (hereafter cited as O'Brien and Mackey interview); OMPE interview, pp. 7, 10 (statement of Melov). OPO retains information on the results of the Hill-Burton CSA reports. OMPE interview, p. 10 (statement of Melov).

⁷² OPO interview, p. 61 (statement of O'Brien).

⁷³ OPO interview, p. 60 (statement of Mackey); OMPE interview, pp. 9, 10 (statement of Melov). See generally HHS, OCR, Regions I-X, annual operating plans, various fiscal years. According to OMPE's director of Management Information and Analysis Division, each year, the OCR regional offices address Hill-Burton facilities in their operating plans. OMPE interview, p. 9 (statement of Melov).

⁷⁴ OMPE interview, p. 9 (statement of Melov); OCR, Hospital Memo, p. 4; OPO interview, pp. 60, 61.

⁷⁵ Ibid.

⁷⁶ OMPE interview, pp. 8-9 (statement of Melov). A hospital's service area is the geographical area from which the hospital draws, or is supposed to draw, the bulk of its inpatients. See HHS, OCR, Analysis of Civil Rights Data Training Workbook, prepared by Support Services International, Inc., April 1998, p. 10 (hereafter cited as OCR, Data Analysis Training Workbook).

⁷⁷ OMPE interview, pp. 8-9 (statement of Melov).

⁷⁸ Ibid., p. 8 (statement of Melov).

⁷⁹ Ibid., p. 9 (statement of Melov).

⁸⁰ Ibid. According to OMPE staff, a national data system was developed under contract for 1995 and 1996, but "the system failed." Ibid.

⁸¹ Ibid.

⁸² Ibid.

Enforcement Based on the Hill-Burton Survey

Based on their examination of the CSA reports from Hill-Burton recipients, the regional offices identified several facilities for compliance reviews, some of which were initiated in 1997.⁸³ Regional offices were instructed by OCR headquarters to give the highest priority to the facilities that had the highest disproportion of underservice to all minority populations, followed by the facilities that had the highest disproportion of underservice for one or more specified minority populations, facilities with the greatest potential LEP compliance problems, and facilities with the greatest disproportion of emergency room transfers based on method of payment.⁸⁴

The annual operating plans reflect that OCR regional offices have various reasons for selecting particular Hill-Burton facilities for review.⁸⁵ For example, Region I identified two Hill-Burton facilities whose CSA reports reflected disproportional services to racial/ethnic minorities. In addition, Region I identified approximately 20 Hill-Burton facilities throughout New England whose census data indicated that at least one language minority group was 10 percent or more of the facility service area; but the facilities did not indicate that their geographic service area included any LEP groups.⁸⁶ Region VI⁸⁷ planned to determine if several Hill-Burton facilities were providing effective services to persons with limited English proficiency. The region targeted these facilities because the data reported on their surveys indicated a "high probability" they were violating title VI.⁸⁸

OCR does not rely solely on the data in the CSA reports to select Hill-Burton facilities for compliance review.⁸⁹ Region VII staff, for instance, will supplement the CSA form with in-

formation such as the complaints received by a facility or the community's perception of a particular facility.⁹⁰ The Region VII manager acknowledges the limited racial/ethnic data collected on the CSA form and that it cannot be used to perform analyses to determine compliance violations by facilities such as public health clinics.⁹¹ He stressed that the CSA form was used only as a "targeting instrument" and that recipients are primarily identified for compliance reviews based on complaints.⁹²

Similarly, the Region IV⁹³ manager stated that the region supplements information on the CSA form with knowledge about the communities around the facilities and that the staff keep abreast of the geographic areas throughout the region "pretty well."⁹⁴ Furthermore, Region IV staff said they also rely on information gathered when a complaint is filed and they obtain data from a recipient Hill-Burton facility.⁹⁵ Region I staff stressed that OCR did not intend regional offices to rely solely on their analyses of data on the facilities' CSA forms to target Hill-Burton facilities for compliance reviews.⁹⁶ Rather, the regions are expected to supplement these data with their knowledge about the facilities, such as complaints received and views held by community residents about the facilities' treatment of patients.⁹⁷

CSA Report Deficiencies

The most recent Hill-Burton survey collected data on patients' racial/ethnic status in only two general areas: inpatient admission and emergency services. Thus, if a facility did not provide these two types of services (such as a public health clinic or certain rehabilitation centers), it did not report racial/ethnic data on beneficiaries

⁸³ *Ibid.*, p. 10 (statement of Melov).

⁸⁴ OCR, FY 1998 AOP guidance, tab C, p. 2.

⁸⁵ *Ibid.*, tab C.

⁸⁶ OCR Region I, FY 1998 AOP.

⁸⁷ Region VI covers Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

⁸⁸ HHS, OCR, Region VI, FY 1998 Annual Operating Plan (hereafter cited as OCR, Region VI, FY 1998 AOP).

⁸⁹ Steve Melov, director, Management Information and Analysis Division, Office of Management Planning and Evaluation, OCR, HHS, telephone interview, p. 4 (hereafter cited as Melov interview). *See, e.g.*, OCR Region VII EOS interview, p. 4 (statement of Kemp); Carter interview, p. 7.

⁹⁰ OCR Region VII EOS interview, p. 4 (statement of Kemp).

⁹¹ Halverson interview, p. 9.

⁹² *Ibid.*

⁹³ Region IV covers Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

⁹⁴ Chretien interview, p. 12.

⁹⁵ Lloyd Gibbons and Henry Barber, equal opportunity specialists, Region IV, OCR, HHS, telephone interview, Feb. 10, 1999, p. 4 (hereafter cited as OCR Region IV EOS interview).

⁹⁶ Chang interview, p. 12; OCR, FY 1998 AOP guidance, tab C, p. 3.

⁹⁷ Chang interview, p. 12.

served.⁹⁸ The absence of a larger, more inclusive sample, limits OCR's capacity to enforce civil rights laws in the health care industry. However, the director of OMPE's Management, Information, and Analysis Division, Steve Melov, said that there was no loss of information by not assessing the racial/ethnic composition of patients served by Hill-Burton outpatient facilities, public health clinics, rehabilitation centers, and other health care facilities that do not provide emergency and/or inpatient services; hospitals are almost 70 percent of Hill-Burton grantees.⁹⁹ He added that most of the 1,200 Hill-Burton public health centers are State-run and were established to provide health care to poor, usually minority, underserved populations. That is, these outpatient facilities intentionally target individuals who could encounter discrimination by other facilities. Thus, according to Mr. Melov, it is unlikely that a public health clinic could be charged with discrimination or a violation of the community service assurance provision.¹⁰⁰ Regardless of this view, OCR is responsible for monitoring recipients of Federal funds with respect to compliance with civil rights laws and should be concerned with a wider application of its data collection efforts.

Another deficiency of the CSA form is that it does not ask any facility to report on the race, ethnicity, or gender composition of recipients of specific health care services and procedures.¹⁰¹ Therefore, the form cannot reveal whether members of different racial and ethnic groups are treated differently in receiving the various

inpatient (e.g., coronary care), outpatient (e.g., renal dialysis), clinical (e.g., laboratory tests), and community services and procedures offered by a health care facility.

Further, according to one regional manager, the information collected by the form may be inaccurate. For example, some institutions are unaware of their service areas, such as a hospital in Harlem that identified all of Manhattan in its service area.¹⁰² Thus, if a facility reports information that does not adequately reflect the service area, OCR cannot make accurate evaluations of the facility's compliance with civil rights requirements.

As the Commission reported in its title VI report in 1996, the Hill-Burton CSA form does not separate sufficient information concerning potential and actual program participants, beneficiaries, or affected communities by race/ethnicity, to enable OCR to identify potential title VI violations, such as barriers to health care services by racial/ethnic minority communities.¹⁰³ In addition, the CSA form does not collect any information on the gender composition of patients admitted or served. Thus, the form cannot be used to determine facility compliance with title IX with respect to teaching hospitals and other educational facilities within HHS' jurisdiction.¹⁰⁴ Moreover, gender discrimination is covered for recipients of Hill-Burton funding under the act's community assurance provision which states that such facilities shall make their services available "without discrimination on the ground of race, color, national origin, creed, or any other ground unrelated to an individual's need for service or the availability of the needed service in the facility."¹⁰⁵ Overall, the Hill-Burton community service assurance form is inadequate for OCR to assess a health care facility's compliance with title VI and the CSA provisions.

Because the data from the survey must be supplemented with other information, by itself it is not useful for the purposes for which it was intended. However, private research has shown that the survey, in tandem with other information, can be used to determine where discrimina-

⁹⁸ Melov interview, p. 4; OMB no. 0990-0209. Note: Facilities that do not provide inpatient or emergency services are instructed to omit the questions on patients' racial/ethnic composition and method of payment. See OMB no. 0990-0209, p. 2; OMB no. 0990-0209, p. 3. During previous survey years, OCR submitted a CSA form to the entire universe of Hill-Burton facilities (i.e., hospitals, nursing homes, public health clinics, rehabilitation centers, other outpatient facilities, home health agencies). However, budget restrictions and requirements to limit burden on survey respondents compelled OCR to disseminate the CSA form only to Hill-Burton hospitals for the latest survey. Melov interview, p. 4.

⁹⁹ Melov interview, p. 4. Mr. Melov further noted that hospitals are more than 90 percent of the Hill-Burton facilities targeted for followup compliance reviews, based on data reported on the CSA form. The remaining Hill-Burton facilities that undergo compliance reviews tend to be nursing homes, many of which are affiliated with hospitals. *Ibid.*

¹⁰⁰ *Ibid.*

¹⁰¹ See, e.g., OMB no. 0990-0096; OMB no. 0990-0209.

¹⁰² Carter interview, p. 7.

¹⁰³ USCCR, *Federal Title VI Enforcement*, p. 248.

¹⁰⁴ OMPE interview, pp. 7, 9 (statements of Malester and Melov).

¹⁰⁵ 42 C.F.R. § 124.603(a)(1) (1998) (emphasis added).

tion occurs in the health care industry.¹⁰⁶ Unfortunately, OCR does not appear to use the form with supplemental information to conduct studies designed to uncover discrimination.

OCR's data collection efforts are inadequate in other respects. For example, the frequency of data collection seems insufficient to provide an adequate assessment of facilities' compliance with their community assurance requirements. OCR has been criticized for the infrequency of its Hill-Burton data collection efforts. According to one scholar:

The value of the race data in [the triennial Hill-Burton survey] is limited by the government's decision to collect it only every three years and by a lack of resources that prevents OCR from publishing the data in aggregate form. The government would not be making even these tentative efforts at data collection were it not for pressure from private civil rights litigants.¹⁰⁷

OCR's staff argued that the CSA form's frequency of administration is sufficient, because it takes 18 months to 2 years for the facilities to complete their reports and subsequently have OCR collect, analyze, and report on the data.¹⁰⁸ Similarly, OMPE staff argued that requiring facilities to submit Hill-Burton CSA reports more frequently than every 3 years would not allow a sufficient cycle for reporting analysis, assessment, review, or outreach.¹⁰⁹

¹⁰⁶ For example, one researcher studied the extent and consequences of racial segregation in hospitals and nursing homes using Hill-Burton reports for the State of Pennsylvania and data from the National Center for Health Statistics. The research found that whites were almost twice as likely as blacks to reside in nursing homes, and white recipients of supplemental security income were 3.52 times more likely than black recipients to be in a nursing home. See David Barton Smith, "The Racial Integration of Health Facilities," *Journal of Health Politics, Policy and Law*, vol. 18, no. 4 (winter 1993), pp. 855-61 (hereafter cited as Smith, "Racial Integration").

¹⁰⁷ Gordon Bonnyman, Jr., "Commentary: Unmasking Jim Crow," *Journal of Health Politics, Policy, and Law*, vol. 18, no. 4 (winter 1993), p. 874 (citations omitted) (hereafter cited as Bonnyman, "Unmasking Jim Crow").

¹⁰⁸ OPO interview, p. 52 (statement of O'Brien).

¹⁰⁹ OMPE interview, pp. 9-10 (statement of Melov). In fact, OMPE is concerned that administering the CSA report on a triennial basis may be too frequent; and staff are beginning an assessment process for the next cycle of reporting to determine whether OCR should modify the CSA instrument or its analysis, and determine what OCR should be doing to enhance this aspect of HHS enforcement compliance pro-

gram. It is crucial that OCR collect accurate information that can assist its staff in determining the extent of compliance with and violations of civil rights statutes relating to health care. Accurate and complete data are important "for understanding the impact of health policy on the health of racial and ethnic groups."¹¹⁰ The CSA form could be used to address a broader segment of the health care industry and to collect more information that would assist OCR in ensuring compliance with civil rights laws and regulations.

Limitations of OCR's Current Data Collection *Haphazard Collection of Data*

According to the regional managers of OCR Region I and Region IV, civil rights enforcement data collected by the equal opportunity specialists varies on a case-by-case basis, and therefore by each civil rights compliance and enforcement activity conducted.¹¹¹ However, several regional managers noted that their offices do not disseminate *any* standard civil rights data collection instruments on an ongoing basis to the HHS recipients in their respective regions.¹¹² The Commission recognizes the importance of tailoring data requests to the specific issues being investigated and requesting information such as the race, color, and national origin of the population eligible to be served; the location of existing or proposed facilities and information regarding whether the location

gram. According to OMPE staff, if facilities submitted CSA reports more frequently, OCR would need to reduce the magnitude of its review of the reports. OMPE is concerned that reminding Hill-Burton facilities of their reporting requirement every 3 years is also too frequent, and that OMB could potentially accuse HHS of jeopardizing the paperwork reduction efforts by requiring facilities to submit CSA reports more frequently. *Ibid.*

¹¹⁰ Smith, "Racial Integration," p. 865; Bonnyman, "Unmasking Jim Crow," p. 875.

¹¹¹ Chang interview, p. 11; Chretien interview, p. 12.

¹¹² Chang interview, p. 11; Chretien interview, p. 12; Halverson interview, p. 8; Ira Pollack, regional manager, Region IX, OCR, HHS, telephone interview, Feb. 17, 1999, pp. 9-10 (hereafter cited as Pollack interview). OCR staff state that these data, and other information necessary to assist OCR in assessing recipients' potential title VI compliance problems, are obtained during an investigation or compliance review. OMPE interview, p. 7 (statement of Melov); PSPS interview, pp. 26-27 (statement of Haynes); Chang interview, p. 11; Chretien interview, p. 11; Halverson interview, p. 8; Pollack interview, pp. 9-10.

could have the effect of denying access to any person on the basis of race/ethnicity and/or gender; the racial/ethnic and gender composition of program participants; or the use of bilingual employees to work with program participants and other beneficiaries who have limited English proficiency.¹¹³ However, it also is important that a *standard* set of data elements be *routinely* requested from HHS recipients. Data collected from all HHS funding recipients should include information on enrollments, treatments, and health care utilization, by race, ethnicity, and sex. Having the appropriate data will assist OCR in identifying potential violations before they become systemic in nature. The analysis of such data is particularly critical given the “life and death” nature of these issues.

Many data request letters written by OCR to facilities undergoing investigations and compliance reviews do not even address all of the data elements that HHS is required to collect, and do not consistently request the same data. Rather than taking a broad-based approach that would allow OCR to view the recipient’s operations as a whole, OCR focuses on isolated elements. For example, in investigating a complaint of discrimination on the basis of sex, race, and national origin at an optometry college, OCR staff in Region I requested only two types of information: transcripts and contact information for the student’s academic advisors.¹¹⁴ In a complaint involving disability and a State department of youth services, Region I asked for the agency’s nondiscrimination policies, the complainant’s files, and information on subrecipients (including client profile, mandate, programs, and services).¹¹⁵ For a compliance review, Region I staff requested information on policies on provision of auxiliary aids for individuals with disabilities, procedures for obtaining auxiliary aids, training on how to use auxiliary aids, nondis-

crimination notices, grievance procedures, and efforts to disseminate notices and procedures.¹¹⁶

Data requests differ not only by type of enforcement activity, but among the regions as well. Region V,¹¹⁷ for example, requested 19 types of information for a review on both age discrimination and the provision of interpreters and bilingual services to non-English-speaking, limited-English-speaking, and hearing-impaired persons. The information requested included a list of all services provided by the health department, documentation of staff training, a list of bilingual staff and interpreters, policies on auxiliary aids, data on the racial and ethnic population of the service area, and information on clients served.¹¹⁸ Comparatively, for a compliant investigation concerning refusal of treatment based on method of payment, Region VII requested information only on the hospital’s position on the complainant’s allegations, the hospital’s procedures for emergency services, and “any Hospital record of this incident.”¹¹⁹ These varying examples demonstrate the inconsistencies in requesting policies, beneficiary and employment data, and other information necessary for determining if discrimination indeed occurred. In addition, not one of the letters requested information on prior complaints or lawsuits filed against the facility. Further, the data requested appear insufficient for statistical testing and drawing conclusions on the existence of discrimination.

The chief civil rights attorney in Region IV said that data elements such as “who was admitted, the types of services provided, and the amount of time taken by a facility to treat beneficiaries with services” lay the foundation for OCR to do an analysis that can reveal a

¹¹³ Chang interview, pp. 11–12; Chretien interview, pp. 11–12.

¹¹⁴ Linda Yuu Connor, chief, Operations Branch I, Region I, OCR, HHS, letter to Larry R. Clausen, president, New England College of Optometry, Boston, MA, Nov. 9, 1994 (re: complaint no. 01–94–3092), p. 2.

¹¹⁵ Jeremiah Maloney, director, Operations Division, Region I, OCR, HHS, letter to William O’Leary, commissioner, Department of Youth Services, Commonwealth of Massachusetts, Boston, MA, Mar. 6, 1995 (re: complaint no. 01–94–3094), p. 2.

¹¹⁶ Jeremiah Maloney, director, Operations Division, Region I, OCR, HHS, letter to Kevin Concannon, commissioner, Maine Department of Human Services, Augusta, ME, Sept. 30, 1996 (re: review no. 01–96–7423), pp. 1–2.

¹¹⁷ Region V covers Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

¹¹⁸ Arturo Garcia, equal opportunity specialist, Region V, OCR, HHS, letter to Nancy Westphalt, director, Kane County Health Department, Geneva, IL, Nov. 7, 1997 (re: docket no. 05987004), pp. 2–5.

¹¹⁹ John Halverson, regional manager, Region VII, OCR, HHS, letter to W. David Drew, administrator, Shenandoah Memorial Hospital, Shenandoah, IA, Nov. 13, 1995 (re: reference no. 07953109), p. 1.

recipient's potential compliance problems.¹²⁰ However, he acknowledged that the HHS title VI regulation on compliance information is vague with respect to specifying the type of information recipients must collect, retain, and furnish to OCR and a time limit for HHS recipients to submit data requested by OCR. Consequently, according to the attorney, Region IV has not "ever" moved forward and attempted to withhold or suspend or terminate recipients' grant funds, even if recipients do not provide data that are needed to assess their compliance with civil rights statutes.¹²¹

The regional attorney also stated that recipients do not always keep the "right information" that OCR may need at a given time. However, because of the vague title VI data collection regulation, those recipients cannot be cited for "keeping the wrong information." Even when recipients have "turned over to OCR all the data they have collected within a given year," they still may not have adequate information for OCR to assess title VI compliance.¹²² When this occurs, Region IV will ask recipients to collect and retain, for a specific monitoring period, a certain type of racial/ethnic data. Recipients can be found in noncompliance only if they are told in advance that they need to collect and retain a specific type of racial/ethnic data, and are not able to provide it when OCR makes a request. Without specific guidelines from HHS on the kind of data recipients must collect and maintain, OCR is significantly hindered in its ability to assess accurately potential compliance violations.

Absence of Recipient and Beneficiary Database

Regional offices do not maintain data and information on the total number of HHS recipients within the region.¹²³ For instance, the regional manager in Region I stated that her office does not maintain data on the names or the total number of HHS recipients within the region. In fact, the region's database does not contain any information on HHS recipients on a consistent basis, except for medicare providers who receive

reimbursement funds from HCFA.¹²⁴ Such information would be useful for planning and conducting compliance reviews in a systematic fashion. Further, regional offices have expressed that they have difficulty deciphering program funds allocated to a State agency (or any HHS recipient), since many recipients tend to participate in numerous HHS programs and receive their allocations in one "lump sum."¹²⁵ Thus, regions have difficulty identifying and monitoring HHS funding recipients.

OCR also has limited data on beneficiaries and potential beneficiaries of HHS funds. The director of the Management Information and Analysis Division within OMPE contends that "nearly everybody" is a potential participant or beneficiary of HHS programs, particularly for medicare and medicaid. Thus, it would not be possible for OCR to identify and maintain racial/ethnic data on an ongoing basis on all potential beneficiaries or affected communities.¹²⁶ He also noted that, because of the many grant programs within HHS and the thousands of recipients, OCR cannot collect, maintain, and analyze compliance data on every applicant. In addition, operating divisions restrict their data collection efforts to determining program effectiveness and would not collect data to determine racial/ethnic or gender discrimination in the programs they administer.¹²⁷ Further, according to the regional manager in OCR Region VIII, there is a historic reluctance among HHS recipients to collect racial/ethnic data or deal with any civil rights obligation.¹²⁸ The manager said that OCR headquarters should provide guidance on how and why recipients should collect data.¹²⁹ Moreover, at least one OCR attorney has stated that she believes that guidance for investigative staff is needed in methodology of handling cases in

¹²⁰ Roosevelt Freeman, regional civil rights attorney, Region IV, OCR, HHS, telephone interview, Feb. 10, 1999, p. 10 (hereafter cited as Freeman interview).

¹²¹ *Ibid.*, p. 11.

¹²² *Ibid.*

¹²³ Chang interview, p. 11; Pollack interview, p. 10.

¹²⁴ Chang interview, p. 11.

¹²⁵ OCR Region II EOS interview, p. 5; Chang interview, p. 2; OCR Region VIII EOS interview, p. 9.

¹²⁶ OMPE interview, p. 6 (statement of Melov).

¹²⁷ *Ibid.*, p. 7 (statement of Melov).

¹²⁸ Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, telephone interview, Feb. 10, 1999, p. 7 (hereafter cited as Kyle-Holmes interview).

¹²⁹ *Ibid.*

which OCR is denied access to information based on confidentiality or privacy issues.¹³⁰

Failure to Use Existing Data Sources

Most State agencies and health providers already collect data on patients, participants, and beneficiaries. These data are used to analyze health status and personal health problems, research populations at risk for certain diseases and illnesses, and assess the quality and availability of services provided and received.¹³¹ Further, health care organizations have developed databases for storing administrative and billing information, clinical records, and other information on patients treated in medical facilities.¹³² Although there are privacy and security concerns with the collection of such data,¹³³ the existence of the many sources of data suggests that it is, indeed, conceivable that similar all-encompassing databases could be devised and/or compiled into a system that could be used for civil rights related research and enforcement.

HHS' enforcement of civil rights is hindered by its lack of effort to collect, maintain, and analyze race/ethnicity data on client access and participation across the health care industry, which can cause discrimination to go unnoticed or be unaddressed due to lack of evidence to prove a title VI violation.¹³⁴ In an effort to improve the collection of data on race, ethnicity, and sex, HHS' Data Council (on which OCR actively participates) is currently developing an HHS-wide data collection strategy, including coordination and integration of surveys and oversight of surveys and general statistical analysis.¹³⁵ Although the data obtained from

HHS national surveys are based on samples and cannot be used to target compliance activities or serve as background for an investigation, the information gleaned from HHS databases that include race/ethnicity fields can be used to assess program access and expenditures.¹³⁶

Failure to Become Involved in Data Collection Efforts within HHS

OCR has failed to collaborate with agencies within HHS that already collect health data, such as the Health Care Financing Administration (HCFA).¹³⁷ HCFA currently uses a billing form known as HCFA-1450 to collect information on each transaction between a medicare or medicaid patient and a health care provider.¹³⁸ An electronic counterpart to this form also exists.¹³⁹ In a recent Federal court case, *Madison Hughes v. Shalala*,¹⁴⁰ health care advocacy groups argued that HHS was required to collect

Secretary for Planning and Evaluation, HHS, telephone interview, Dec. 23, 1998, pp. 2-3 (hereafter cited as Scanlon interview). For example, one of the projects of the Data Council is an update of the HHS "Directory of Minority Health Data," which was developed in the 1970s and most recently revised in 1995. Scanlon interview, p. 2; OMPE interview, pp. 5-6 (statement of Melov); Melov interview, p. 5. The directory is an inventory of each HHS database that has program beneficiary/participant data, as well as data from national surveys, including the National Medical Expenditure Survey, the Medicare Current Beneficiary Survey, the Medicaid Statistical Information System Personal Summary File, and the National Health Interview Survey. HHS, "Directory of Minority Health and Human Services Data Resource: Table of Contents," accessed at <<http://www.os.dhhs.gov/progorg/aspect/minority/mintoc.htm>>, pp. 1-5.

¹³⁶ OMPE interview, p. 6 (statement of Melov).

¹³⁷ See Bonnyman interview, pp. 2-4. See also Marianne Engelman Lado, professor, School of Public Affairs, Baruch's College, telephone interview, Jan. 11, 1999, p. 24 (hereafter cited as Lado interview).

¹³⁸ See 8-92 HCF-1450 (billing/claim form) and "Bill Review: HCFA-1450" (instructions for completing HCFA-1450), no date, pp. 6-25 to 6-64, accessed at <<http://www.hcfa.gov/medicare/edi/edi.htm>> (hereafter cited as HCFA-1450 billing form).

¹³⁹ See HHS, Health Care Financing Administration, "Medicare A 837 Health Care Claim," Apr. 1, 1998, pp. 3-6, accessed at <<http://www.hcfa.gov/medicare/edi/edi3.htm>> (hereafter cited as HCFA, A 837 Health Care Claim). This form may soon become the industry standard. See Health Insurance Reform: Standards for Electronic Transactions, 63 Fed. Reg. 25,272 (1998) (to be codified at 45 C.F.R. pt. 142) (proposed May 7, 1998).

¹⁴⁰ Civil Action No. 3:93 0048 (M.D. Tenn. June 4, 1993) (dismissed for lack of subject matter jurisdiction), *aff'd*, 80 F.3d 1121 (6th Cir. 1996).

¹³⁰ Velveta Golightly-Howell, regional attorney, Region VIII, OCR, HHS, telephone interview, Feb. 11, 1999, p. 3 (hereafter cited as Golightly-Howell interview).

¹³¹ National Research Council, Computer Science and Telecommunications Board, For the Record: Protecting Electronic Health Information (Washington, DC: National Academy Press, 1997), p. 73 (hereafter cited as National Research Council, For the Record).

¹³² *Ibid.*, pp. 20-21.

¹³³ See generally *ibid.*

¹³⁴ Jane Perkins, "Race Discrimination in America's Health Care System," *Clearinghouse Review*, special issue, 1993, p. 377 (hereafter cited as Perkins, "Race Discrimination").

¹³⁵ HHS, "HHS Data Council: Introduction," p. 2; "HHS Data Council: Long-Term Agenda," July 24, 1996, accessed at <<http://aspe.os.dhhs.gov/datacncl/ltagenda.htm>>. See also James Scanlon, director, Division of Data Policy, Assistant

patient- and provider-specific data from recipients as part of its title VI enforcement regime and that the billing form should be altered to collect data on race and ethnicity of patients.¹⁴¹ This form collects information about medicare and medicaid patients, such as patient name, address, birthdate, gender, dates of service, diagnosis codes, treatment authorization codes, specific services provided and respective dates, total charges and noncovered charges, and physicians' signatures.¹⁴²

The plaintiffs in *Madison-Hughes*, as well as many health care interest groups, believed that the inclusion of a race data element in the form would greatly improve efforts to detect instances of race discrimination against patients.¹⁴³ If a race data element were added to form 1450 (or form A 837), it would be possible to determine if individuals with similar diagnoses received similar treatment by a particular health care provider or physician. A health care advocate who represented some of the plaintiffs in *Madison-Hughes* asserts that form 1450 is used for privately funded health care services as well as for those financed through medicare and medicaid.¹⁴⁴ This would mean that comparisons of diagnosis and treatment could be performed using samples taken from the entire patient population, not just medicaid and medicare patients. Moreover, collecting race data in this fashion would be more cost effective and less burdensome for providers than creating a new, independent survey form that would be completed separately.

However, the plaintiffs' case failed, and HCFA was not required to modify its form. Neither were advocates able to persuade HCFA to do so voluntarily, even though it was undisputed that HCFA has the authority to collect such racial/ethnic data.¹⁴⁵ In a discussion paper on the subject, HCFA offered several justifications for not amending form 1450. For example, HCFA officials asserted that patients would be sensi-

tive about supplying race information.¹⁴⁶ This argument is weakened by the fact that health care providers already note the races of their patients in their medical records. In addition, HCFA said it applies what it asserted is a "basic concept of transaction processing." HCFA stated that this concept, applied to the race data issue, would dictate that race data are "static" and therefore should not be collected on the claims form, which collects information that is "dynamic."¹⁴⁷ However, the form already collects information on gender and date of birth, which are static characteristics. HCFA also argued that imposition of the race data element would be opposed by insurers, who would view it as unnecessary, undesirable, and burdensome.¹⁴⁸ The discussion paper also claimed the addition of a race component to the form would damage public relations, and that the quality of the data would be uneven because different providers would guess at the races of patients rather than asking the patients to self-identify.

Finally, HCFA stated that the integrity of its database would be undermined by the data processing demands associated with the additional information on race, which it argued was already being collected through its enrollment forms.¹⁴⁹ Instead of modifying the form 1450, HCFA proposed cross-matching patient information on the unchanged form to enrollment databases. This method would be time consuming and thus costly, and in many cases, this method would result in incomplete data because medicare enrollment forms before 1982 only coded for "white," "black," or "other," and because many providers do not accept medicaid.¹⁵⁰

Thus, presumably as a result of this discussion paper and related negotiations with OMB, the HCFA-1450 was not altered to include a data element for the patient's race. Nor does form A 837 currently request such information.¹⁵¹ This bureaucratically driven decision, apparently based upon HCFA's concern for its relationships

¹⁴¹ See Bonnyman interview, pp. 2-4.

¹⁴² See HCFA-1450 billing form.

¹⁴³ See Gordon Bonnyman, Legal Aid Society of Tennessee, letter to Harriet Rabb, general counsel, HHS, Feb. 16, 1995, pp. 1-3 (re: *Madison-Hughes v. Shalala*, no. 94-6626 (6th Cir.), collection of race data on health access/utilization) (hereafter cited as Bonnyman letter).

¹⁴⁴ Bonnyman interview, p. 4.

¹⁴⁵ 80 F.3d 1131 (6th Cir. 1996).

¹⁴⁶ Health Care Financing Administration, discussion paper on HCFA Race Data, undated, p. 1.

¹⁴⁷ *Ibid.*

¹⁴⁸ *Ibid.*

¹⁴⁸ *Ibid.*

¹⁴⁹ *Ibid.*, p. 2.

¹⁵⁰ See Bonnyman letter, p. 4.

¹⁵¹ HCFA, A 837 Health Care Claim, app. C.

with industry insurers, its image, and the increased data processing demands nullified what was potentially one of the most effective solutions to the challenge of documenting discrimination by health care providers.

Summary

HHS must improve and expand its reporting requirements and data collection activities in order to better assess and ensure prospective and current recipients' compliance with civil rights statutes (and ensure that health care programs are administered/delivered in a nondiscriminatory manner). With such efforts, OCR could be alerted to recipients' potential compliance problems, and thereby reduce the chances of complaints of racial/ethnic or gender discrimination arising in HHS health care programs. Consequently, OCR could reduce the use of staff and financial resources currently used for complaints investigations and potential litigation. According to a staff attorney with the National Health Law Program (NHLP), HHS' neglect of collecting data on the racial/ethnic backgrounds on health care service beneficiaries is long standing.¹⁵² Other than the triennial collection of very limited race/ethnicity data from the Hill-Burton facilities, HHS has not universally required federally subsidized health care providers to record, much less report, data that would be minimally necessary to assess their compliance with title VI.¹⁵³ From the NHLP attorney's perspective, HHS' enforcement of civil rights is hindered by its lack of effort to collect race/ethnicity data on client use across the health care industry, which can cause charges of discrimination to go unreported and remain unaddressed due to lack of evidence to prove a title VI violation.¹⁵⁴

Another attorney highlighted the importance of data collection for civil rights enforcement. She stated that it was "unconscionable" that data collection did not keep up with the changes in the health care industry. She noted that data collection is crucial for determining the basis for any kind of subsequent investigation.¹⁵⁵

Preaward and Postaward Reviews, and Complaint Investigations

The Attorney General, through the Department of Justice (DOJ), Coordination and Review Section (CORS), is authorized to oversee the civil rights enforcement programs of the Federal agencies responsible for enforcing civil rights statutes. Executive Order 12250 and DOJ's own coordination regulations require DOJ to provide enforcement support. However, they also allow DOJ considerable discretion to determine the nature of this assistance.¹⁵⁶ The CORS title VI regulations provide Federal agencies with standards for funding approval, investigative procedures, and compliance methods.¹⁵⁷ Further guidance is provided by the DOJ title VI guidelines,¹⁵⁸ and the DOJ title VI legal and investigative manuals.¹⁵⁹ DOJ advises each agency on developing its enforcement program, particularly compliance investigations and technical assistance.¹⁶⁰

OCR defines its approach to conducting its compliance reviews, both preaward and postaward, and complaint investigations, in procedural guidance developed by headquarters staff.¹⁶¹ OCR's procedural manuals, along with its regulations, policies, and other guidance provide the basis—the blueprint—for the agency's civil rights enforcement operations. Currently, OCR uses its *Case Resolution Manual* (CRM) to provide procedural guidance for conducting compliance reviews and complaint investigations

¹⁵⁶ See Exec. Order No. 12,250, 3 C.F.R. 298 (1981), reprinted in 42 U.S.C. § 2000d-1 (1994 & Supp. II 1996). See generally 28 C.F.R. §§ 42.401-42.415 (1998).

¹⁵⁷ 28 C.F.R. §§ 42.401-42.415 (1998).

¹⁵⁸ 28 C.F.R. § 50.3 (1998).

¹⁵⁹ See U.S. Department of Justice, Civil Rights Division, *Title VI Legal Manual*, September 1998; U.S. Department of Justice, Civil Rights Division, *Investigation Procedures Manual for the Investigation and Resolution of Complaints Alleging Violations of Title VI and Other Nondiscrimination Statutes*, September 1998 (hereafter cited as DOJ, *Title VI Investigative Procedures Manual*).

¹⁶⁰ See generally Merrily Friedlander, chief; Ted Nickens, deputy chief, Programs; Allen Payne, program officer; Andrew Strojney, deputy chief, Legal; Coordination and Review Section, Civil Rights Division, U.S. Department of Justice, interview in Washington, DC, Jan. 26, 1999.

¹⁶¹ Cushing interview, p. 4; Floyd Plymouth, Delores Braun, Gloria Silas-Webster, and Fay Dow, equal opportunity specialists/investigators, Region X, OCR, HHS, telephone interview, Feb. 2, 1999, p. 16 (statement of Plymouth) (hereafter cited as OCR Region X EOS interview); Pollack interview, p. 5.

¹⁵² Perkins, "Race Discrimination," p. 377.

¹⁵³ *Ibid.*

¹⁵⁴ *Ibid.*

¹⁵⁵ Lado interview, pp. 23-24.

under all of the statutes it enforces.¹⁶² Until 1996 OCR relied on its *Investigative Procedures Manual* as its primary means of ensuring investigative staff were properly trained in conducting compliance reviews and complaint investigations.¹⁶³ In 1996 OCR replaced the *Investigative Procedures Manual* with the *Case Resolution Manual*, which covers procedures for conducting complaint investigations, compliance reviews, preaward reviews for medicare providers, and implementing the block grant compliance program. A careful examination of the CRM reveals some of the major deficiencies characterizing OCR's processes and practices employed in conducting civil rights enforcement activities.

The CRM's introduction reiterates the mission of OCR and explains the manual's development:

The mission of the Office for Civil Rights (OCR) in the Department of Health and Human Services (HHS) is to promote and ensure that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination. The Case Resolution Manual (Manual) provides OCR with the tools to accomplish these objectives promptly and effectively and to maximize the impact of existing resources.¹⁶⁴

Also in the introduction, OCR identifies several broad principles on which the procedural guidance in the manual is based. First, OCR states that the CRM is not a "prescriptive" document, but one that offers "flexibility," while establishing "general parameters within which a variety of resolution approaches can be appropriately utilized."¹⁶⁵ Along these lines, OCR notes that it has had "considerable success with the use of existing formal and informal means to help resolve disputes between parties."¹⁶⁶ However, OCR states that it needs to "examine and expand, where appropriate and feasible, the use of additional **Alternative Dispute Resolution (ADR) methods.**"¹⁶⁷

¹⁶² OCR, CRM.

¹⁶³ See HHS, OCR, *Investigative Procedures Manual* (hereafter cited as IPM).

¹⁶⁴ *Ibid.*, "Introduction."

¹⁶⁵ *Ibid.*

¹⁶⁶ *Ibid.*

¹⁶⁷ *Ibid.*

The second broad principle on which OCR bases its case processing activities is "a strong belief in the merit of teamwork: within the investigative team, within each region, and between each OCR component."¹⁶⁸ Further, OCR states that it places a premium on "consultation and a willingness to take responsibility."¹⁶⁹ The third principle on which OCR bases its compliance review and complaint investigation procedures is "communication and involvement," which the CRM states are "essential to effective case processing."¹⁷⁰ OCR indicates that it will provide the appropriate level of communication and involvement through frequent meetings and written status reports "circulated to everyone and clearly defining the involvement of each team member."¹⁷¹ These three broad principles provide a sound basis for conducting civil rights enforcement.

OCR indicates that one of its main goals in conducting enforcement activity is "securing system compliance."¹⁷² Numerous experts on civil rights law in the health care context, including litigators, legal scholars, and professional researchers, agree that OCR has failed utterly to pursue the kind of large scale systemic compliance review and litigation that could reduce racial and ethnic disparities in health care access, financing, research, and treatment.¹⁷³ The lack of aggressive title VI enforcement is evident in OCR's failure to develop systemic enforcement in key areas of the Nation's health care system such as the managed care industry and medicaid. OCR's Region II is now working on a case in Nassau County, New York, involving allegations of discrimination. However, this case was brought to OCR's attention only after investigative reporters for a television network uncovered the discrimination.¹⁷⁴

¹⁶⁸ *Ibid.*

¹⁶⁹ *Ibid.*

¹⁷⁰ *Ibid.*

¹⁷¹ *Ibid.*

¹⁷² See *ibid.*

¹⁷³ See generally Jane Perkins, National Health Law Program, telephone interview, Feb. 5, 1999, pp. 2-3 (hereafter cited as Perkins interview). Lado interview; Bonnyman interview.

¹⁷⁴ Fernando Morales, attorney, Region II, Office of General Counsel, HHS, telephone interview, Feb. 3, 1999, p. 3 (hereafter cited as Morales interview).

Although OCR states one of its main priorities is to secure compliance, much of the CRM focuses only on procedures for conducting complaint investigations.¹⁷⁵ To address the kind of broad-based structural civil rights concerns indicated by significant racial disparities in health care status and quality of care, large-scale systemic compliance reviews are a more effective tool than individual complaint investigations. Therefore, more thorough, detailed procedural guidance on conducting compliance reviews would help strengthen the CRM as procedural guidance and emphasize more forcefully the importance of large-scale onsite compliance reviews in addressing systemic discrimination in the health care industry.¹⁷⁶

The CRM also needs a more significant discussion on collecting statistical and other data necessary for compliance reviews. The current discussion in the CRM does not emphasize the importance of statistical evidence because it is too brief and does not address specifically the different kinds of statistical data necessary for establishing proof of a systemic level violation. However, statistical evidence is invaluable in conducting compliance reviews and complaint investigations.¹⁷⁷

For showing both intentional and disparate impact discrimination, statistics play a crucial role. A finding of a title VI violation by OCR may require statistical evidence to show that the recipient engaged in a policy or practice that resulted in discrimination on the basis of race, color, or national origin, whether the recipient intended to practice such discrimination or whether the practice was neutral with respect to intent, but nonetheless caused an adverse impact. For OCR to show that a recipient is engaging in intentional discrimination on the basis of race, statistical evidence may be used to lend credibility to claims of discrimination made by individuals in complaints. The CRM, however, does not contain a section on the kinds of statistical data that would be necessary to show a title VI violation in different kinds of cases using spe-

cific examples of the uses of statistical data in both disparate impact and disparate treatment cases.

The CRM also is very brief and cursory in its procedural guidance for compliance reviews and complaint investigations. For example, the manual does not include thoroughly detailed implementation and enforcement procedures particular to HHS' block grant programs; nor does it specifically address how OCR uses the disparate treatment and disparate impact theories in fashioning approaches to establishing cases of discrimination; nor does it include step-by-step instructions for implementing title VI, from the application and preaward process through compliance review and complaint processing, in each type of program HHS sponsors.¹⁷⁸ This is especially important for State-administered programs, such as continuing State programs and block grant programs.¹⁷⁹ Since those programs' civil rights compliance components are managed by State and local recipients, rather than by HHS, they involve special and more complicated enforcement issues related to OCR's oversight and monitoring of States' title VI implementation efforts. It is critical that both OCR staff and State recipients understand how to conduct the title VI enforcement mechanisms particular to such programs.

OCR intentionally developed the CRM in a streamlined format to make it more accessible and user-friendly to investigative staff.¹⁸⁰ However, in doing so, OCR created a manual that is not sufficiently thorough to provide investigative staff with the kind of comprehensive desk reference. One regional manager noted that the CRM can be used as a desk reference, but it must be used in connection with other policies, regulations, and resources pertaining to investigative work to do thorough and effective investigations.¹⁸¹ A second, more far-reaching effect of the CRM's lack of detailed guidance may be a negative impact on OCR's ability to integrate effective title VI enforcement into every type of HHS grant program, particularly block grants. By

¹⁷⁵ Ibid.

¹⁷⁶ OCR is currently working on a draft substantive compliance manual. When finished, its issue-specific investigation procedures may meet this need to some extent. See vol. II, chap. 3, for a discussion of the intended role of this document and a review of its chapter on patient-dumping.

¹⁷⁷ See above for a discussion of the need for data collection.

¹⁷⁸ The appendices, however, do contain the procedures for block grants, but do not provide details on the enforcement of nondiscrimination provisions of block grant statutes.

¹⁷⁹ See below for a discussion of OCR's oversight and monitoring of continuing State programs.

¹⁸⁰ Kyle-Holmes interview, p. 4.

¹⁸¹ Ibid.

trying to ensure balance between the need for thoroughness and the desire to keep the manual simple is reasonable, OCR appears to have sacrificed thoroughness and detail.

One means of addressing the need for thoroughness and detail in its procedural guidance for investigative staff is to ensure dissemination and familiarity with the title VI investigative procedures manual recently issued by DOJ/CORS.¹⁸² This document, released to title VI enforcement agencies in September 1998, is far more thorough, detailed, and comprehensive as procedural guidance. CORS developed this document in response to the many requests from Federal civil rights enforcement agencies to prepare guidance on investigative techniques.¹⁸³

Where OCR's CRM is slightly over 50 pages, the CORS manual contains more than 200 pages and many sections that the CRM does not. These include sections on applicable legal theories, such as disparate treatment and disparate impact; a description of the evidence required to complete investigations under these theories; methods for analyzing evidence; and far more detailed sections on settlement agreements, letters of finding, and investigative reports. The CORS manual also contains 28 appendices covering topics such as interviewing techniques and monitoring checklists. Compared with the CRM, it is by far the more complete and useful document.

In addition to dissemination of the CORS manual, OCR could seek to enhance the CRM by changing the presentation of the manual. For example, OCR could develop a more indepth manual but provide the document to staff in a binder with multiple, removable parts separated by tabs. Using this approach, OCR could develop a more detailed, comprehensive manual while allowing staff to focus only on the sections they feel are most useful to them in conducting investigative work.

The discussion below addresses how well OCR implements the procedures it discusses in the CRM. The focus of the discussion is on the process OCR undertakes in conducting the kind of enforcement activity that it performs: preaward and postaward compliance reviews; and complaint investigations. For each enforcement activity, the process of enforcement from plan-

ning and priorities, to procedures and outcomes, including findings and administrative and legal proceedings, are addressed.

Assurances Before Releasing Funds

OCR begins its efforts to ensure compliance among recipients of Federal financial assistance before the release of Federal funds. Under DOJ guidance, OCR requires all applicants of funding programs to submit assurances of compliance with laws prohibiting discrimination.¹⁸⁴ As part of the HHS application process, prospective recipients of Federal financial assistance (e.g., loans, contracts, cooperative agreements, property, or other financial assistance) from HHS must sign a comprehensive statement certifying their compliance with Federal civil rights statutes that prohibit discrimination on the basis of race/ethnicity, color, national origin, gender, age, and disability.¹⁸⁵

An assurance of compliance form is an agreement in which a recipient legally agrees to administer its programs and services in accordance with title VI and other civil rights provisions pursuant to the grant agreement, contract, or appropriation—an agreement to use program funds in a nondiscriminatory manner.¹⁸⁶ The applicant's signature means that civil rights compliance is a condition for receiving Federal funds and that HHS has the right to seek judicial enforcement of the assurance.¹⁸⁷

The DOJ coordinating regulations require "at a minimum"—as a condition prior to receiving Federal funds—that recipients of Federal funds (including State agencies participating in block grant programs) sign statements assuring that they will administer their federally financed programs in a nondiscriminatory manner.¹⁸⁸

¹⁸⁴ O'Brien and Mackey interview, p. 6.

¹⁸⁵ HHS, OCR, Office of Program Operations, "Assurance of Compliance," May 1997 (hereafter cited as HHS FORM 690).

¹⁸⁶ See USCCR, *Federal Title VI Enforcement*, p. 171; Arkansas, Louisiana, New Mexico, Oklahoma, and Texas State Advisory Committees, report to the USCCR, *The New Wave of Federalism: Block Granting and Civil Rights in the Southwest Region*, January 1983, p. 8 (hereafter cited as *The New Wave of Federalism*).

¹⁸⁷ HHS, Form 690, p. 2. HHS OCR devised HHS Form 690. OPO interview, p. 15.

¹⁸⁸ See 28 C.F.R. § 42.407(b) (1998); USCCR, *Federal Title VI Enforcement*, pp. 3, 9, 171 (for State agencies) and pp. 8, 83, 171 (for other applicants seeking Federal assistance); *The New Wave of Federalism*, p. 8.

¹⁸² See DOJ, *Title VI Investigative Procedures Manual*.

¹⁸³ *Ibid.*, p. 6.

DOJ coordinating regulations require that, prior to approval of Federal financial assistance, Federal agencies must make written determination as to whether the applicant is in compliance with title VI.¹⁸⁹ As a basis for this determination, agencies should rely on the submission of an assurance of compliance and a review of the data submitted by the applicant.¹⁹⁰ Where a determination cannot be made from these data, the regulations require the applicant to submit "necessary additional information" and require the agency to take steps such as communicating with local government officials or minority organizations and conducting field reviews.¹⁹¹ In addition, the regulations state, "Where the requested assistance is for construction, a pre-approval review should determine whether the location and design of the project will provide service on a nondiscriminatory basis and whether persons will be displaced or relocated on a nondiscriminatory basis."¹⁹²

Similarly, HHS title VI regulations require that every application for HHS financial assistance contain an assurance that the program will be conducted in compliance with all Federal requirements imposed by or pursuant to title VI.¹⁹³ HHS title VI regulations require that every application by a State or State agency contains a statement that the program is (or, in the case of a new program, will be) conducted in compliance with all requirements under title VI.¹⁹⁴

Along with the civil rights assurance form, OCR reviews other documents to demonstrate an applicant institution's civil rights compliance before granting funding. According to OCR, these documents may include the applicants' nondiscrimination policy, section 504 grievance

procedure, patients' rights handbook, and age-related policies for compliance with applicable civil rights laws.¹⁹⁵ OCR also informed the Commission that once an institution has established its civil rights compliance through filing an assurance form, that institution's status remains in effect permanently, unless the facility undergoes a change of ownership or other significant organizational, policy, or practices change that requires the submission of a new assurance form.¹⁹⁶ OCR did not list a finding of liability in a civil rights lawsuit as one of the reasons why it would require an institution to undergo a new assurance process.

Preaward Reviews

Preaward reviews are extremely valuable because they allow Federal agencies to discover discrimination before Federal funds are given out. Preaward reviews can also be used to require applicants to take preventive measures to ensure that discrimination will not occur in their programs as a condition of receiving funds. Thus, preaward reviews are essential to preventing title VI violations before they take their toll on potential beneficiaries and participants. Furthermore, desk-audit preaward reviews are an effective means of targeting State or local continuing program recipients that may need technical assistance or more extensive onsite review. However, HHS only performs these reviews on medicare recipients. For all other funding recipients, beyond assurances signed at the time funds are allocated, there is no requirement to give annual or more frequent reports on civil rights activities (e.g., what technical assistance and outreach the facility has done).

Conducting Preaward Reviews

OCR's *Case Resolution Manual* contains a brief section on conducting pregrant reviews for facilities applying to participate in medicare programs, the only program for which OCR requires preaward reviews.¹⁹⁷ OCR examines an applicant's "civil rights posture" when it applies

¹⁸⁹ 28 C.F.R. § 42.407(b) (1998).

¹⁹⁰ See *id.* OCR estimates that, as of June 1999, it has over 75,000 such assurance forms on file. See Thomas E. Perez, OCR, HHS, letter to Frederick D. Isler, assistant staff director, USCCR, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 10, item 21 (hereafter cited as Perez letter, June 3, 1999, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions").

¹⁹¹ See 28 C.F.R. § 42.407(b) (1998).

¹⁹² *Id.*

¹⁹³ 45 C.F.R. § 80.4(a)(1) (1998).

¹⁹⁴ *Id.* § 80.4(b)(1); USCCR, *Federal Title VI Enforcement*, p. 220.

¹⁹⁵ Perez letter, June 3, 1999, "HHS OCR Headquarters Follow-up Questions," p. 10, item. 20.

¹⁹⁶ *Ibid.*, pp. 10-11, item 22.

¹⁹⁷ O'Brien and Mackey interview, p. 6.

for participation in the medicare program.¹⁹⁸ However, because OCR performs these reviews on new medicare applicant facilities and medicare providers only,¹⁹⁹ many of HHS other federally assisted program applicants and recipients receive funds without undergoing a preaward review process beyond the signing of an assurance form to ensure compliance with title VI and nondiscrimination in their programs.

OCR's *Investigative Procedures Manual* provided detailed instructions for conducting medicare preaward clearance reviews. Before clearance is granted, OCR staff must collect from the applicant and review data on:

- The racial and ethnic composition of the applicant's service area.
- The racial and ethnic composition of the applicant's contract staff by type of position held.
- If the applicant's service area has more than 100 LEP persons, the applicant's methods for serving LEP clients, including whether the applicant has bilingual contact staff.²⁰⁰

The staff also must collect and review additional data from hospitals, such as the number of beds, the number of patient admissions over a 2-week period by race and ethnicity, the number of LEP patients served, and the number of doctors associated with the hospital by race and ethnicity. Similar data are required for nursing homes, home health agencies, rural health agencies, hospices, and comprehensive outpatient rehabilitation facilities.²⁰¹ If a review of these data or other information obtained by staff suggests that the applicant might not be in compliance with title VI, staff may conduct an onsite review of the applicant.²⁰²

¹⁹⁸ Ronald Copeland, associate deputy director, Office for Program Operations; Marcella Haynes, director, Policy and Special Projects Staff; Pamela Malester, deputy director, Quality Assurance and Internal Control Division; OCR, HHS, interview in Washington, DC, July 29, 1998, p. 3 (hereafter cited as OCR interview, July 29, 1998).

¹⁹⁹ USCCR, *Federal Title VI Enforcement*, p. 226. See HHS, *Report of the HHS Civil Rights Review Team*, September 1993, p. 11 (hereafter cited as HHS, *Civil Rights Review Team Report*).

²⁰⁰ OCR, IPM, chap. 18, p. 11.

²⁰¹ *Ibid.*, pp. 11–12.

²⁰² *Ibid.*, p. 4.

The procedures manual did not explain the objective in reviewing these data. For instance, the manual does not state that staff should determine whether minority and nonminority participation in a recipient's program are comparable, nor does it instruct staff to consider the recipient's staffing patterns for indications that there might be discrimination in the recipient's program delivery. Absent such provisions, comprehensive staff training is crucial to ensuring that OCR staff perform these preaward reviews efficiently and effectively.

It is not clear whether the preaward reviews actually conducted by OCR are satisfactory to determine compliance with civil rights statutes and regulations. In Region VII, OCR staff indicated that as long as they receive the data they requested (policies, self-evaluations, posted notices, etc.), the applicant is certified.²⁰³ The Region VII staff said that during the preaward review they want to make sure the applicants have policies for communicating with deaf and LEP patients. In this region, staff said that preaward reviews are conducted by equal opportunity assistants, not equal opportunity specialists.²⁰⁴ Further, it appears that preaward reviews largely are "paper" reviews and are not conducted onsite at the applicant's facility.²⁰⁵

Outside the medicare context, OCR's current method of simply ensuring that applicants for HHS funding have signed the appropriate assurance form is a very *de minimus* approach to its preaward review activity. One reason for the lack of attention to this area is the already heavy OCR workload. In FY 1998, for example, OCR staff conducted 4,035 pregrant reviews of applicants for medicare participation. Nonetheless, vigorous title VI enforcement requires more thorough means of ensuring that recipients of Federal funding are complying with nondiscrimination requirements before becoming recipients of Federal funds. The limited focus of HHS preaward review process impedes an effective title VI compliance and enforcement program. Without a preaward review mechanism, potential and actual program beneficiaries may experience the adverse effects of discriminatory practices before HHS can identify and address

²⁰³ OCR Region VII EOS interview, p. 2.

²⁰⁴ *Ibid.*

²⁰⁵ Pollack interview, p. 6.

them at the postaward stage. However, with strong proactive efforts such as desk-audit reviews before allocation of funding, Federal agencies such as HHS can better ensure that Federal funding recipients are not practicing illegal discrimination.

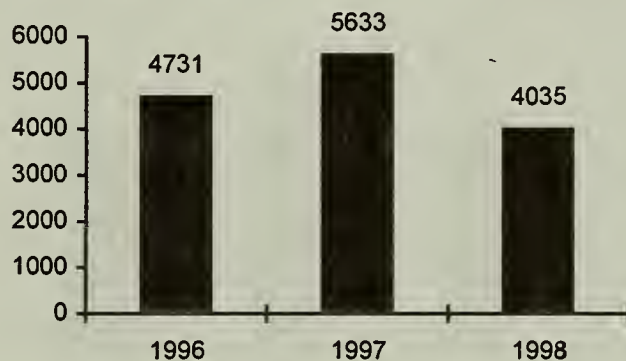
In 1998 OCR began a pilot project on automated pregrant reviews. Phase I of the project involves the distribution of a "national Automated Pregrant Data Request Package" by hard copy, e-mail, or Internet, to applicants for medicare certification.²⁰⁶ The data request package includes an information sheet explaining the OCR information request; a list of information requested, such as name and address of facility, administrator's name, contact person, number of employees, corporate affiliation, nondiscrimination policies and notices; and information on LEP and other policies. The package also includes information on how to establish effective nondiscrimination policies and notice procedures, how to establish effective communication procedures, information on section 504 and the Age Discrimination in Employment Act, definitions, and a section 504 self-evaluation checklist.²⁰⁷ Although this package contains valuable information, it leaves out much, such as a complete description of title VI. Further, it is only provided to applicants for medicare certification. Thus, valuable tools, such as the section 504 self-evaluation checklist, which could be adapted to other civil rights statutes, are not distributed more widely to recipients of and applicants for Federal funding.

Analysis of OCR's Case Processing Database: Preaward Reviews

Pregrant reviews occupy much of OCR staff time. In many of the regions, a large proportion of resources is spent on pregrant reviews. The preaward review workload was heaviest in Regions IV, V, VI, and IX.²⁰⁸ Seventy percent of the total FY 1998 review workload was in these four regions. OCR's primary responsibilities are to:

(1) investigate complaints, (2) perform compliance reviews, (3) provide technical assistance, and (4) perform pregrant award reviews. Once complaints and compliance reviews are factored in, remaining resources are then distributed to technical assistance and pregrant award reviews.²⁰⁹ But, in three of the above regions, excluding Region IV, preaward reviews accounted for 52 to 66 percent of the total workload of the region.²¹⁰ Thus, these regions have little time for other enforcement-related activities.

Figure 4.1
OCR's Total Pregrant Review Workload, FY 1996-1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996-1998.

OCR's pregrant review workload varies.²¹¹ During the early 1980s, the number of pregrant reviews conducted by OCR rose significantly, due to changes in medicare regulations that allowed home health agencies to participate. In FY 1984, OCR performed 3,275 pregrant reviews. But after 1984, the number of reviews that OCR conducted, fell considerably and continued this downward trend throughout the early 1990s. By FY 1993, the number of pregrant reviews conducted by OCR had increased to 3,073, ap-

²⁰⁶ Ronald G. Copeland, associate deputy director, Office of Program Operations, memorandum to regional managers, Regions I thru X, Aug. 26, 1998 (re: automated pregrant review data request project), p. 1 (hereafter cited as Copeland, pregrant review memo).

²⁰⁷ Copeland, pregrant review memo, attachment, "OCR Pregrant Automation Project."

²⁰⁸ See app. 4.1.

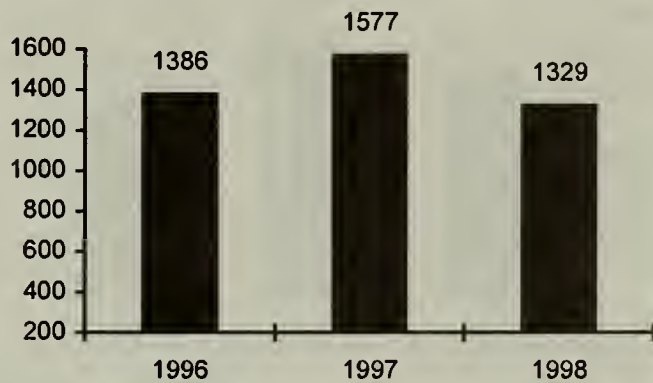
²⁰⁹ Cushing interview, p. 3.

²¹⁰ HHS, OCR, Regions IV, FY 1998 Annual Operating Plan, Table D (hereafter cited as OCR Region IV, FY 1998 AOP, Table D); HHS, OCR, Regions V, FY 1998 Annual Operating Plan, Table D (hereafter cited as OCR Region V, FY 1998 AOP, Table D); OCR Region VI, FY 1998 AOP, Table D; HHS, OCR, Regions IX, FY 1998 Annual Operating Plan, Table D.

²¹¹ USCCR, *Funding Federal Civil Rights Enforcement*, clearinghouse publication no. 98, June 1995, pp. 226-28 (hereafter cited as USCCR, *Funding Federal Civil Rights Enforcement*).

proaching the 1984 total. As shown in figure 4.1, the total pregrant review workload peaked again at 5,633 in FY 1997, a 19 percent increase from the previous fiscal year. Between FY 1997 and FY 1998, OCR's total pregrant award workload decreased again by 29 percent. The FY 1998 pregrant award workload was 15 percent lower than the FY 1996 workload.²¹² Also during this period, HHS experienced a steep decline in the number of full-time employees. The total number of full-time employees fell from 437 in FY 1984 to 313 employees by FY 1992.²¹³

Figure 4.2
OCR's Total Pregrant Reviews Carried-in,
FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

The total pregrant review workload includes those pregrants received in the current fiscal year and those pregrants carried into the current fiscal year from the previous fiscal year (figures 4.2 and 4.3).²¹⁴ As shown in figure 4.2, in FY 1996, 29 percent of the pregrant reviews were carry-ins from FY 1995. Twenty-eight per-

²¹² HHS, OCR, Case Activity Tracking System Database, FY 1998 (hereafter cited as OCR, CATS Database). During this time, OCR's full-time staff continued to decrease, but the decrease during fiscal years 1993 to 1997 was not as significant as during fiscal years 1983 to 1992. Between fiscal years 1993 and 1997 OCR lost a total of 71 full-time employees. OCR, "Budget and FTE Usage History."

²¹³ HHS, OCR, "OCR Budget and FTE Usage History, FY 80–FY 99 est.," Oct. 5, 1998 (hereafter cited as OCR, "Budget and FTE Usage History").

²¹⁴ For example, the FY 1998 pregrant review workload included 2,706 pregrant reviews that were received in FY 1998 and 1,329 pregrant reviews that were carried-in from FY 1997.

cent of the FY 1997 reviews were carry-ins from FY 1996. By FY 1998, 33 percent of reviews were carry-ins from the previous fiscal year.²¹⁵ Between fiscal years 1995 and 1998, OCR lost a total of 42 full-time employees, which could explain in part the continuous rise in the percentage of pregrant work that has been carried into previous fiscal years.²¹⁶ As shown in figure 4.3, between FY 1996 and FY 1997 the number of pregrant reviews increased by 711 reviews. However, between FY 1997 and FY 1998 the number of preaward reviews decreased by 1,350.²¹⁷

The number of open and closed pregrant award reviews varied by region. Regions II and IX were the only regions in which the number of closed pregrant award reviews nearly equaled the number of open reviews at the end of fiscal year 1998. The workload in Region II consisted of 118 pregrant reviews; only 58 percent of these reviews were closed in FY 1998. Only 54 percent of the 550 pregrant award reviews in Region X²¹⁸ were closed in FY 1998.²¹⁹ Two possible factors contributing to the high percentage of unclosed reviews in these two regions are both regions have a relatively small compliance staff and both regions also are more complaint driven than other regions.

Pregrant reviews are a critical element of civil rights enforcement. Therefore, the need to conduct more thorough pregrant reviews must be balanced against the constant problem of insufficient funding. However, it is possible for OCR to find ways of conducting more vigorous enforcement at the preaward stage that is time and cost effective. One means of conducting more thorough preawards of nonmedicare recipients in the absence of more funding may be for OCR to conduct a desk-audit review on a specific number of funding recipients. For example, OCR could conduct desk-audit reviews of 10 percent of its applicants. By relying on sophisticated software packages to perform statistical analyses that can decrease the time needed to conduct a desk audit from several weeks to a matter of 3

²¹⁵ OCR, CATS Database.

²¹⁶ OCR, "Budget and FTE Usage History."

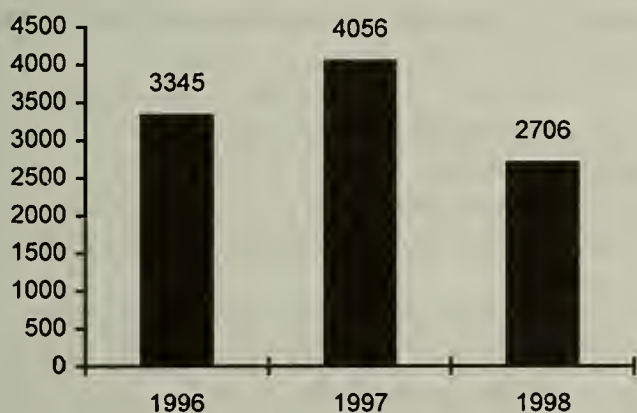
²¹⁷ OCR, CATS Database.

²¹⁸ Region X covers Arkansas, Idaho, Oregon, and Washington.

²¹⁹ OCR, CATS Database.

days, OCR investigative staff could conduct these preaward desk audits without sacrificing an inordinate amount of time. The level of enforcement activity OCR conducts at the preaward stage could increase significantly through these or similar means. HHS operating divisions do not conduct preaward reviews, although most of them require assurances of nondiscrimination.²²⁰

Figure 4.3
OCR's Total Pregrant Reviews Received,
FY 1996-1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996-1998.

Postaward Reviews

After Federal funds have been awarded, recipients may be targeted for postaward compliance reviews.²²¹ OCR's regional offices have primary responsibility for onsite compliance reviews of recipients.²²² DOJ's coordination regulations require each Federal title VI enforcement agency to implement "an effective program of post-approval compliance reviews."²²³ These reviews are to include "periodic submission of compliance reports by recipients" and may involve field reviews of some recipients.²²⁴ The regulations also require that any findings from these reviews be written and that notice be given to the Assistant Attorney General for Civil

²²⁰ USCCR, *Federal Title VI Enforcement*.

²²¹ OPO interview, pp. 30-33 (statements of Patricia Mackey).

²²² USCCR, *Federal Title VI Enforcement*, p. 228.

²²³ 28 C.F.R. § 42.407(c)(1) (1998).

²²⁴ *Id.* § 42.407(c)(1).

Rights if they result in findings of noncompliance.²²⁵

All HHS compliance reviews are initiated by OCR, and are divided into two categories, limited scope and full scope.²²⁶ Limited-scope reviews focus on a particular issue or problem usually under a single statute, while full-scope reviews cover a broader statutory scope, generally addressing all of the protected classifications under a statute.²²⁷ The regional manager has the authority to turn a limited-scope review into a full-scope review.²²⁸

Limited-scope reviews also differ from full-scope reviews in the approach used for conducting them. With limited-scope reviews, OCR screens recipients by desk-audit review to determine whether an onsite review is appropriate.²²⁹ Limited-scope reviews are attractive primarily because they can be accomplished more quickly and with fewer resources than onsite compliance reviews. However, the emphasis of both full-scope and limited-scope reviews is to ensure that HHS programs are in compliance with the civil rights statutes prohibiting discrimination.²³⁰

The vast majority of OCR's postaward reviews are limited-scope desk-audit reviews in which it usually addresses only one issue relevant to civil rights in health care. For example, in recent years, one issue that frequently has been the subject of limited-scope reviews has been limited English proficiency.²³¹ However,

²²⁵ *Id.* § 42.407(c)(2),(d).

²²⁶ OCR interview, July 29, 1998, p. 3.

²²⁷ *Ibid.*; HHS, OCR, *Case Activity Tracking System (CATS) Procedures Manual*, August 1998, chap. 1, pp. 2-3.

²²⁸ OCR, CRM, p. 24.

²²⁹ USCCR, *Federal Title VI Enforcement*, p. 228.

²³⁰ OCR interview, July 29, 1998, p. 3.

²³¹ OCR, FY 1998 AOP Guidance, p. 2. For example, the annual operating plan for Region II scheduled 90 limited-scope reviews, all of which focused on LEP and hearing-impaired individuals. However, the office did not include any new full-scope compliance reviews in its operating plan that year. HHS, OCR, Region II, FY 1997 Annual Operating Plan. In 1998 the operating plans for Regions I, II, and VII scheduled 20, 46, and 31 new limited-scope reviews, respectively, of which LEP-focused reviews accounted for 17, 20, and 25 of the reviews, respectively. Moreover, Regions I and II did not include any new full-scope reviews in their operating plans, while Region VII included only 3. OCR Region I, FY 1998 AOP; HHS, OCR, Region II, FY 1998 Annual Operating Plan (hereafter cited as OCR Region II, FY 1998 AOP); HHS, OCR, Region III, FY 1998 Annual Operating Plan

OCR's emphasis on limited-scope reviews that only evaluate one issue indicates a misappropriation of its resources, because these reviews are not as comprehensive as desk-audit reviews that encompass one or more statutes, and nowhere near as comprehensive as onsite reviews. Given the complexities involved in assessing the presence of discrimination, particularly racial discrimination, in the health care industry, OCR's emphasis on limited-scope reviews addressing a single issue appears glaringly inadequate and ineffective as a means of maximizing scarce resources. Moreover, a large percentage of HHS funding recipients still do not undergo any kind of postaward review process.

Planning and Priorities

Compliance Review Planning

OCR engages in planning activities to provide focus to regional staff and to develop ways to more effectively conduct its compliance reviews.²³² During the 1990s, OCR planned enhancements for its compliance reviews, as well as other proactive steps to eliminate discrimination in certain target areas.²³³ For example, through its strategic plan pilot projects, OCR is working to reduce staff time allocated to complaint processing and to reallocate staff to post-grant and voluntary compliance and outreach work.²³⁴ The agency has also sought to target compliance reviews in specific areas, such as managed care organizations, to determine whether their contracting practices with providers produced discriminatory barriers to medical services.²³⁵

In planning its compliance review activity each year, OCR relies on its annual operating plan guidance,²³⁶ the primary means through which OCR headquarters communicates with the regional offices to set annual priorities for compliance reviews. The AOP guidance provides a number of priorities each year. However, OCR headquarters allows a significant amount of flexibility in how the regions will conduct their

compliance review activity.²³⁷ This is important because each region is very different demographically and geographically. For example, LEP issues may be far more relevant in Regions VII and IX, which include States with major LEP populations, such as California, Arizona, and New Mexico, whereas it may not be as significant in other regions.²³⁸

FY 1998 Program Priorities

According to OCR headquarters' FY 1998 annual operating plan guidance, the most recent AOP provided to the Commission, OCR's "programmatic priorities" for civil rights enforcement in the health care context for FY 1998 included:

- Limited English proficiency.
- Managed care.
- Hospital services.
- Other health care and social services delivery systems.
- Presidential/Secretarial initiatives on race.
- Departmental initiative on adult immunization and vaccine safety.
- Title VI/title IX applied to federally conducted programs.²³⁹

For each of the programmatic priority areas, OCR identified specific objectives for compliance reviews. For example, the AOP guidance memorandum required each region to conduct at least one compliance review during FY 1998 addressing limited English proficiency and managed care.²⁴⁰ According to the AOP guidance, these priorities "support the commitments we have made in our GPRA Annual Performance Plan and the goals for our Strategic Plan."²⁴¹

Certainly the program priorities are clear on identifying a particular issue on which to focus. For example, based on a review of monthly "Significant Activities Reports" submitted by the regions to OCR's Office of Program Operations, there appears to be an overwhelming emphasis

(hereafter cited as OCR Region III, FY 1998 AOP). See below for a discussion of OCR's compliance review workload.

²³² USCCR, *Federal Title VI Enforcement*, p. 229.

²³³ *Ibid.*

²³⁴ *Ibid.*

²³⁵ *Ibid.*

²³⁶ See chap. 2.

²³⁷ Pollack interview, p. 2.

²³⁸ *Ibid.*, pp. 2, 7.

²³⁹ OCR, FY 1998 AOP guidance, p. 1.

²⁴⁰ *Ibid.*, p. 2.

²⁴¹ *Ibid.*, p. 1.

on limited English proficiency.²⁴² In the context of LEP, it appears that OCR has a clear idea of what its objectives are and the forms of noncompliance it is seeking to eradicate. In addition, the AOP requires that each region perform a compliance review addressing limited English proficiency.

However, the AOP guidance does not require that each region perform a compliance review for all of the priorities. For example, for the initiative on other health care and social services delivery systems, which supports HHS' Secretarial initiative on quality of health care, the guidance recommends, but does not mandate, that OCR staff perform compliance reviews.²⁴³ It appears, based on the AOP guidance, that HHS has not placed the same emphasis on this initiative as it has placed on limited English proficiency. Given that this initiative is focused on continuing inequities based on race specifically in the context

of important areas such as health care financing, insurance, and evolving health care delivery systems, a stronger emphasis would seem entirely appropriate.

Moreover, OCR's AOP for FY 1998, while requiring or recommending that each region conduct compliance reviews in particular program priority areas, does not contain specific guidance or discussion on developing and implementing investigative plans specifically designed to attain a clearly focused objective. The AOP's lack of specificity on the actual objectives of its planned compliance reviews is an indicator that OCR, both at the headquarters and the regional levels, is not focusing on what it specifically hopes to achieve in conducting a particular compliance review, and how it should conduct the review to reach that objective.

For example, OCR lists managed care and hospital services among the program priorities under which each regional office is required to conduct a compliance review in FY 1998. The AOP states that the objective in requiring each region to conduct at least one compliance review of a managed care program is to increase "the number of managed care plans shown to be in compliance with title VI, section 504, and ADA."²⁴⁴ The AOP states that the goal with respect to managed care is to determine "whether minorities . . . have access to nondiscriminatory services,"²⁴⁵ but nowhere does the guidance discuss the forms of noncompliance for which OCR is searching or the specific objectives it seeks to address with regard to race discrimination under title VI. It also does not identify the specific means the agency would use to establish a showing of noncompliance, nor does it indicate the remedy OCR would seek if a violation were uncovered.

The AOP guidance does not contain a recommendation or requirement that each regional office develop indepth, individualized investigative plans for conducting their compliance reviews. While OCR requires each region to submit an annual operating plan, the discussion of planned activities, including compliance reviews, that are included in the AOP are one-page descriptions that simply identify, in very general terms, each regional office's plans for completing

²⁴² A sampling of just one region's activities for a span of 3 months in 1998 shows the significant emphasis OCR recently has placed on the LEP issue. For example, for the month of February 1998, Caroline Chang, regional manager for Region I, notes an LEP presentation to the Governor's Cabinet at the Augusta, ME, statehouse; a regional briefing on the LEP staff guidance; and 14 separate items under the heading "LEP Complaints and Technical Assistance Activities in Maine." See Caroline Chang, regional manager, Region I, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Mar. 5, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of February 1998). For the month of March 1998, Ms. Chang notes the following LEP-related activities: a compliance review; two new complaints; four pending complaints; and nine activities under the heading "LEP Complaints and Technical Assistance Activities in Maine." See Caroline Chang, regional manager, Region I, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Apr. 2, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of March 1998). For the month of April 1998, Ms. Chang notes a request for technical assistance on LEP issues from Cambridge hospital as result of an LEP "rollout" activity Region I had conducted; eight pending complaints relating to LEP; an LEP "rollout" to the regional meeting of New England Enterprise Communities; a speech on the LEP guidance given by Ms. Chang at a seminar sponsored by the Massachusetts Medical Interpreters Association and Northeastern University's Interpreter Education Project; and a panel discussion on LEP issues led by a Region I EOS at the 1998 Civil Rights Leadership Conference of the Massachusetts Advisory Council to the USCCR. See Caroline Chang, regional manager, Region I, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, May 7, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of April 1998).

²⁴³ *Ibid.*, p. 1 and tab A.

²⁴⁴ *Ibid.*, p. 2.

²⁴⁵ OCR, FY 1998 AOP Guidance, tab A, § II.

compliance reviews, technical assistance, and other activities.²⁴⁶

Aside from the annual AOP guidance, there is little guidance concerning strategies for conducting compliance reviews. One regional civil rights attorney has expressed concerns about the lack of clear focus in identifying both the practices OCR would consider to be title VI race discrimination violations and the means of uncovering these practices.²⁴⁷ According to this attorney, a longstanding problem with OCR compliance reviews has been that often they appear to become "bogged down by lack of investigative focus."²⁴⁸ He stated that OCR's title VI compliance reviews, in the managed care setting in particular, generally display a lack of focus.²⁴⁹ The lack of focus is based on the failure to identify clearly a number of factors, including what kinds of data OCR is seeking, and the lack of background research that might help OCR staff to understand more fully the complexities involved in rooting out discrimination in the health care industry, particularly discrimination on the basis of race.²⁵⁰ In his view:

The planning of the reviews has never involved any specific focus on any particular practice or service. None of the reviews that I can recall were ever sufficiently diagnosis specific to identify data that would be the basis for the comparison. It is a major problem with compliance reviews. They have gotten extremely abstruse and they remain abstruse. . . . The whole compliance review practice is very unsatisfactory because it never defines an issue with enough specificity to be able to say, yes, there is an actual issue posed here that you can test using data.²⁵¹

Based on interviews with OCR regional managers, it appears that OCR is attempting to define the scope of its managed care compliance reviews. One regional manager has indicated some of the specific approaches his staff uses in conducting compliance reviews in the managed care setting.²⁵² He said that his region's compli-

ance reviews in this area have focused on "membership criteria, how people are being solicited, marketing, geographic areas of the plan, outreach activities, and any criteria which may discriminate by race."²⁵³ This is a clearer recitation of the methods OCR uses in conducting its reviews. However, it appears that OCR regional staff do not develop written investigative plans for every compliance review they perform.

Equally important, it appears OCR has placed little priority on title IX issues. Although OCR has developed a program priority for FY 1998 that incorporates title IX along with title VI, OCR regional staff report that they have done no compliance reviews on title IX. The lack of emphasis on ensuring compliance with title IX mirrors the agency's failure to develop adequate regulatory and policy guidance on this statute.²⁵⁴ The agency reports that it receives very few complaints on title IX. For example, the manager in Region VI stated that approximately 60 percent of resources currently go into complaints, but his region has not had any complaints dealing with title IX issues for which HHS conducts enforcement efforts.²⁵⁵

A small number of complaints does not mean that no discrimination is occurring; it may reflect weak efforts by OCR to publicize the law. One regional attorney stated that current forms of discrimination are often subtle and individuals may not be aware of their rights.²⁵⁶ Moreover, a regional manager stated that OCR does not do much to address title IX because of a lack of resources.²⁵⁷ However, in a complaint-driven agency with few resources, if a particular statute enforced by the agency is not the basis for many complaints, by redirecting resources toward compliance reviews on that statute, such an agency can better determine whether discrimination is occurring. In order to do this, at a minimum OCR should make title IX issues a *separate* program priority that requires each region to conduct at least one compliance review a

²⁴⁶ See vol. II, chap. 2.

²⁴⁷ Stewart Graham, chief counsel, Region I, Office of General Counsel/Civil Rights Division, HHS, telephone interview, Feb. 22, 1999, p. 7 (hereafter cited as Graham interview).

²⁴⁸ Ibid.

²⁴⁹ Ibid.

²⁵⁰ Ibid., p. 8.

²⁵¹ Ibid.

²⁵² Pollack interview, p. 7.

²⁵³ Ibid.

²⁵⁴ See vol. II, chap. 3.

²⁵⁵ Ralph Rouse, manager, Region VI, OCR, HHS, telephone interview, Feb. 2, 1999, pp. 2, 6 (hereafter cited as Rouse interview).

²⁵⁶ Bill Rhinehart, regional attorney, Region III, OCR, HHS, telephone interview, Feb. 24, 1999, p. 2 (hereafter cited as Rhinehart interview).

²⁵⁷ Rouse interview, p. 2.

year on title IX issues relating to health care and/or medical study and practice.

Full-Scope vs. Limited-Scope Reviews

In identifying requirements for meeting the objectives under each program priority in its AOP guidance, OCR does not distinguish between full-scope and limited-scope reviews. Whether a review will be limited or full scope depends on the discretion of the regional manager.²⁵⁸ Based on the Commission's evaluation of OCR enforcement activities, OCR conducts far more limited-scope reviews than full-scope reviews in meeting the AOP requirements for program priorities.²⁵⁹ OCR defines limited-scope reviews as "designed to focus on a single issue," although they may focus on more than one issue.²⁶⁰ In recent years the issue on which OCR has based its limited-scope reviews primarily has been limited English proficiency, which addresses national origin discrimination but does not cover race and color, the other two protected classifications under title VI. Such limited-scope reviews can be accomplished more quickly and with fewer resources than onsite compliance reviews. However, OCR's reliance on limited-scope reviews, and haphazard selection of sites for compliance reviews, is a weakness in its overall enforcement program. Using such an approach, OCR fails to enforce all of the civil rights statutes under its care, and thus, fails to ensure equal access and treatment for all protected classes under those statutes. In particular, OCR's emphasis on limited-scope reviews focusing only on the limited English proficiency issue has created two significant problems. First, it has meant fewer full-scale, onsite reviews which are necessary to thoroughly assess compliance in many instances. Second, it has resulted in the neglect of several important classifications under title VI, namely, race and color.

Site Selection

OCR targets recipients for compliance reviews based on a list of national priority issues developed by headquarters staff, or if research or other information, such as lawsuits, complaints, or a history of noncompliance, suggests that they

may have a compliance problem.²⁶¹ Some of the research material used to determine sites for compliance reviews is provided by OCR's Policy and Special Projects Staff (PSPS), which sends weekly information reports to OCR regions. A review of attachments to the weekly reports shows they include newspaper articles, research studies, and scholarly articles. These materials cover a wide range of relevant issues. For example, the October 23, 1998 weekly information report contained the following attachments: a news article from the *Chicago Tribune* reporting on hospitals requiring payment arrangements from women in active labor before administering an epidural (procedure to relieve pain during labor);²⁶² an article from *Emerge* magazine reporting on a study published in the *Journal of American Medical Association* (JAMA) finding that black people, women, and poor people are less likely to receive life-saving kidney transplants than white people, men, and the affluent;²⁶³ and the JAMA article reporting the study, titled "Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor."²⁶⁴

OCR relies on such research to some extent in conducting compliance reviews.²⁶⁵ However, by placing a stronger emphasis on research as a tool for targeting sites for compliance, OCR staff would have a better knowledge of the recipient selected and could more effectively conduct the compliance review. By placing more emphasis on these source materials as the basis for targeting different groups for compliance reviews, OCR would be using a creative means for conducting its site selection targeting activities, from both a geographical and topical standpoint. As one OCR regional manager has stated, more

²⁶¹ See OCR, IPM, p. 1.

²⁶² Karen Brandon, "Some Poor Face Cash Demand During Labor," *Chicago Tribune*, Oct. 1, 1998, pp. 1, 14.

²⁶³ Kathleen Kerr, "Uneven Access to Transplants/Blacks, Poor Less Likely to Get Kidneys," *Emerge Magazine Online*, Oct. 8, 1998, accessed at <<http://www.msbt.com/news/home.asp?number=2>>.

²⁶⁴ G. Caleb Alexander and Ashwini R. Sehgal, "Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor," *Journal of American Medical Association*, vol. 280, no. 13 (Oct. 7, 1998), pp. 1148-52.

²⁶⁵ See Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 14, 1999 (re: request for information), p. 4 (hereafter cited as OCR Region VIII, Response to Information Request).

²⁵⁸ OCR, CRM, p. 24.

²⁵⁹ See discussion below analyzing OCR's case database.

²⁶⁰ OCR, CRM, p. 23.

research on emerging issues and more of a focus on information gathering in preparing to conduct investigations would be beneficial to OCR staff.²⁶⁶

Currently, the compilations sent by PSPS to regional staff are not very extensive. However, regional staff assigned on a rotating basis to significant research projects could be effective for creating much larger compilations of materials. To this end, OCR headquarters could provide specific guidance on available research tools and areas where research is needed. OCR regional offices could assign staff on a rotating basis to the task of briefing newspaper articles and research studies to make recommendations on where OCR should conduct compliance reviews and what issues are relevant. Such staff could make use of research tools such as the Internet and electronic research databases such as LEXIS/NEXIS in conducting this research.

Compliance Review Procedures

In its overview on conducting compliance procedures, OCR's *Case Resolution Manual* provides a very brief discussion containing three sections: general compliance procedures, full-scope reviews, and limited-scope reviews.²⁶⁷ OCR uses the opening paragraphs of this section to set forth its view of the role that compliance reviews should play in rooting out illegal discrimination by recipients of HHS funding. OCR states that the statutes it enforces require it to review "from time to time" the procedures and practices of HHS funding recipients to determine whether they are in compliance with civil rights statutes.²⁶⁸

OCR states that its pivotal objective in conducting a compliance review is "to address comprehensive systemic issues."²⁶⁹ However, the extent to which OCR has been able to achieve that objective, at least with regard to title VI race discrimination, is questionable. For example, despite overwhelming evidence of large-scale racial disparities in access to health care throughout the health care industry,²⁷⁰ it appears that OCR compliance reviews, rarely sys-

temic in nature, often do not address the significant disparities by race, ethnicity, and sex, that are found in almost every health care context imaginable, such as the managed care industry, nursing homes, home health care, medical school admissions, medical research, and minority staff privileges.²⁷¹ Moreover, the CRM itself implies that even when a compliance review indicates a potential violation, OCR will not necessarily investigate. The CRM states, "Whenever a compliance review indicates a potential violation, OCR should offer technical assistance to resolve the matter. Alternately, at the discretion of the Regional Manager, OCR *may* initiate an investigation to more thoroughly examine the underlying issues or to seek legally binding Agreements to effectuate systemic remedies."²⁷² With guidance suggesting a reluctance to investigate a potential violation, rather than a firm proactive stance on compliance, OCR already has hindered its ability to ensure compliance.

Thus, when a potential violation is discovered, the CRM appears to favor technical assistance to the recipient over an expansion of investigative effort. An effective tool in achieving compliance, technical assistance should be an integral aspect of OCR's operations. However, OCR should take care not to overemphasize its utility. If systemic violations arise during a compliance review, OCR should continue to probe into the investigation to discover all underlying issues that may be contributing to a program's disparate effects. Otherwise, the structural conditions that originally created the disparities will persist. However, based on the Commission's evaluation of OCR enforcement activities, the extent to which OCR thoroughly examines underlying issues to effectuate systemic remedies appears to be quite limited.

Contributing to the erosion of OCR's capacity to perform effective compliance reviews is the CRM's failure to emphasize OCR's role in the prevention of systemic discrimination, and to

²⁶⁶ Kyle-Holmes interview, p. 2.

²⁶⁷ See OCR, CRM, pp. 22-23.

²⁶⁸ *Ibid.*, p. 22.

²⁶⁹ *Ibid.*

²⁷⁰ See vol. I, chap. 3.

²⁷¹ See generally Ronald Copeland, associate deputy director; Office of Program Operations, OCR, HHS, documents sent November 1998 in response to USCCR request for information, including Letters of Findings and Other Closures—FY 1998; Letters of Findings and Other Closures—FY 1997; Regional Monthly Significant Activities Reports (hereafter cited as OPO, Response to Information Request). See vol. I, chap. 3 and vol. II, chap. 3.

²⁷² OCR, CRM, p. 22 (emphasis added).

specifically address how to conduct compliance reviews in the above contexts. The CRM's entire section on compliance reviews is only four pages, over two of which are devoted to medicare pregrant reviews. Moreover, the manual's section on compliance reviews does not even contain case resolution and enforcement procedures. It merely cross-references those segments of the complaints section, stating that "[t]he procedures identified in the Manual for complaint resolution and enforcement should be utilized for compliance reviews, as appropriate."²⁷³ With this cursory treatment of such an important OCR function, OCR headquarters should not expect regional staff to even appreciate the purpose of compliance reviews, much less know how to perform them.

In short, the CRM's procedural discussion on postaward compliance reviews places a strong emphasis on technical assistance and outreach and education while providing little else in the way of specific procedural guidance. The CRM states that "[a]ll compliance reviews should include a component for technical assistance and, except for Medicare pregrant reviews, community outreach."²⁷⁴ In addition, it identifies and briefly describes the two kinds of postaward compliance reviews OCR conducts, full scope and limited scope. Beyond this, the guidance merely states that the procedures identified in the CRM for complaint resolution and enforcement should be used for compliance reviews, as appropriate.²⁷⁵

However, given the significant differences between compliance reviews and complaint investigations, this cursory statement appears inadequate. Among the key differences are: compliance reviews are systemic in nature whereas complaint investigations generally are far more limited in scope; the kind of information and data and the means of gathering it may vary significantly between compliance reviews and complaint investigations; and compliance reviews require a carefully planned design before they are begun. At a minimum, the CRM should address the development and implementation of investigative plans for conducting compliance reviews.

The CRM's section on compliance reviews contains a more complete, although still brief, discussion on medicare pregrant clearance reviews.²⁷⁶ However, the compliance review section does not address any other specific topics or issues on which OCR is focusing or might focus on in the future. These include proving disparate impact cases, racial medical redlining, access to health care financing programs such as medicaid and medicare, and participation of women and minorities in health care research programs. Investigatory procedures will differ based on which one of these issues is involved. A more detailed discussion, along the lines of the one the CRM provides on medicare pregrant clearances seems appropriate. The lack of specific procedural discussion on various issues is another example of OCR failing to achieve the proper balance between streamlining and completeness with the CRM.

The procedures OCR identifies for conducting compliance reviews in the CRM provide a cursory overview of the efforts the agency will undertake to determine the presence of compliance violations. However, not only is the CRM discussion on conducting compliance reviews cursory and brief, but the methodology described is routine and focused on generalities such as addressing "comprehensive systemic issues," more thoroughly examining the underlying issues, and providing technical assistance.²⁷⁷ Although the CRM discussion is intended as an overview, it suggests that the actual investigative techniques employed by OCR in conducting compliance reviews could benefit from an infusion of creativity and aggressiveness in identifying illegal discrimination.

One commentator, writing about what he refers to as the "high water mark" of civil rights enforcement in the health care context, the years from 1964 to 1968, notes that this period is "instructive of what is required" to conduct "aggressive enforcement of civil rights compliance."²⁷⁸ He suggests that OCR in 1999 should pattern compliance review activities after those conducted in the 1960s, seeking to collaborate with civil rights activists, organizations, and other interested parties. He describes compli-

²⁷³ Ibid.

²⁷⁴ Ibid.

²⁷⁵ Ibid.

²⁷⁶ Ibid., pp. 23-24.

²⁷⁷ Ibid., p. 22.

²⁷⁸ Smith, *Health Care Divided*, p. 331.

ance efforts undertaken during this period in the following manner:

Civil rights inspection teams during this period did not rely solely upon reports of hospitals and the routine collection of statistical information, or even upon on-site inspections. Data resources were far inferior to what exist today, and the inspectors were usually pulled on temporary assignments from unrelated parts of the federal bureaucracy and often lacked any familiarity with the institutions they were reviewing. They often faced far more determined and hostile adversaries, willing to go to extensive lengths to conceal their actual operations and to circumvent compliance. . . . [One reason for their success is] a network of local civil rights organizations and health services workers, intimately familiar with the operations of local hospitals, did the "real work." Periodic telephone contacts between the president of the NMA [National Medical Association], hired as a part-time consultant to the Office for Equal Health Opportunity, and local physicians helped target problem areas. Local hospital employees, often meeting in secret locations with inspectors the evening before site visits in order to avoid retaliation, would review the floor plans and instruct inspectors about the problem areas. The knowledge that this was part of the procedures circumvented much obfuscation.²⁷⁹

Analysis of OCR's Case Processing Database: Compliance Reviews

Deficiencies in OCR's compliance review activities are exacerbated by staff and resource limitations. OCR's staff is disproportionately small relative to the amount of Federal financial assistance HHS distributes. OCR has devoted the majority of its staff resources to complaint investigations and pregrant reviews, and has devoted few resources to the other civil rights enforcement activities. As a result, few compliance reviews are conducted.²⁸⁰

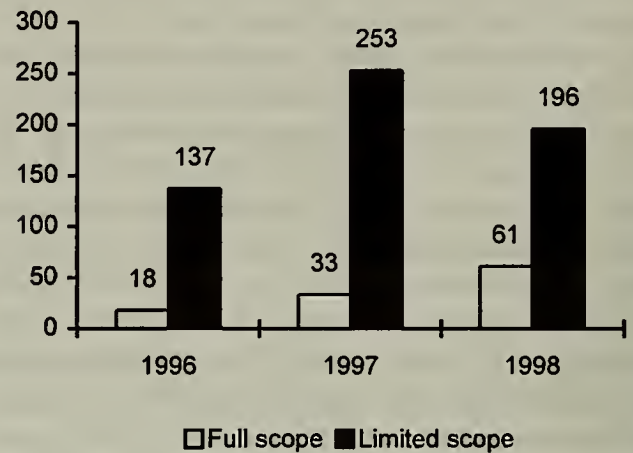
Similar to the pregrant review workload, the compliance review workload decreased in FY 1998, after nearly doubling between fiscal years 1996 and 1997 (see table 4.1). In FY 1998 the compliance review workload consisted of 257 reviews.²⁸¹ Because compliance reviews are un-

²⁷⁹ Ibid.

²⁸⁰ For example, the Commission previously reported that in FY 1993 OCR began only 12 onsite compliance reviews and completed 21 compliance reviews. The previous 5 years averaged 99 such reviews and investigations per year. USCCR, *Funding Federal Civil Rights Enforcement*, p. 229.

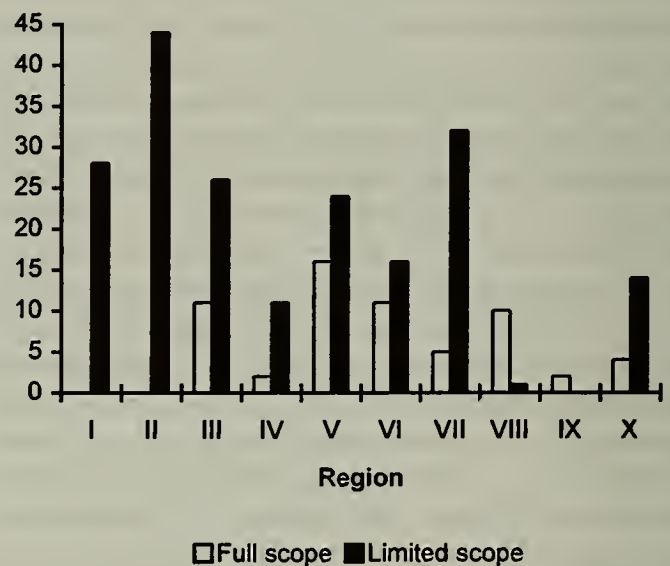
²⁸¹ OCR, CATS Database.

Figure 4.4
OCR's Total Compliance Review Workload, FY 1996-1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996-1998.

Figure 4.5
Compliance Reviews by Region, FY 1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996-1998.

dertaken upon OCR's own initiative, OCR ultimately determines the size of the workload in this particular activity, so it is not unusual to see fluctuations, particularly during the years when resources are limited or budgets have been cut.

Table 4.1
OCR's Compliance Review Workload, FY 1996–1998

	1996	1997	1998	Change FY 1996–97	Change FY 1997–98
Compliance reviews					
<i>Full-scope reviews</i>	18	33	61	83.3%	84.8%
Carry-ins	3	6	13	100.0%	116.7%
New starts	15	27	48	80.0%	77.8%
Closed	12	20	21	66.7%	5.0%
Open	6	13	40	116.7%	207.7%
<i>Limited-scope reviews</i>	137	253	196	84.7%	-22.5%
Carry-ins	14	30	33	114.3%	10.0%
New starts	123	223	163	81.3%	-26.9%
Closed	108	220	135	103.7%	-38.6%
Open	29	33	61	13.8%	84.8%
Total workload	155	286	257	84.5%	-10.1%

SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

In FY 1996, 23 percent of the total compliance review workload remained open at the end of the fiscal year. Although OCR's total compliance review workload increased by 85 percent between fiscal years 1996 and 1997, OCR was able to close more compliance reviews in FY 1997 than in FY 1996. Although the compliance review workload decreased in FY 1998 compared with the previous year, the number of reviews that remained open at the end the year increased from 46 to 101.²⁸²

As shown in figure 4.4, most of OCR's compliance reviews are limited in scope. During FY 1996 and FY 1997, roughly 88 percent of all compliance reviews were conducted as limited-scope reviews. In FY 1998, 76 percent of all compliance reviews were limited scope.²⁸³

As shown in figure 4.5, all OCR regions initiated some form of compliance review in FY 1998. Regions VIII and IX were the only regions in which the full-scope compliance review workload exceeded the limited-scope review workload. In FY 1998 Region IX²⁸⁴ had only two compliance reviews, both of which were conducted as full-

scope reviews.²⁸⁵ In 1999 Region IX is focusing its compliance reviews on the Multiethnic Placement Act.²⁸⁶ In FY 1998, Region VIII had 11 compliance reviews and 10 were full-scope reviews. For FY 1999, Region VIII has roughly 18 limited-scope reviews planned, some of which will be conducted on Hill-Burton facilities.²⁸⁷ The number of planned compliance reviews varies depending on the issues being addressed and on how the region can get the most out of its resources.²⁸⁸

The regional manager in Region I stated that in FY 1998 the region conducted two full-scope reviews related to health care, one of which addressed managed care and the other focused on LEP.²⁸⁹ For FY 1999, Region I has targeted three health maintenance organizations for compliance reviews.²⁹⁰ On the other hand, Region II

²⁸⁵ OCR, CATS Database.

²⁸⁶ Annis Arthur, Bud Ho, and Marla Sagatelian, equal opportunity specialists, Region IX, OCR, HHS, telephone interview, Feb. 18, 1999, p. 3 (statement of Sagatelian) (hereafter cited as OCR Region IX EOS interview). Pub. L. No. 103–382, 108 Stat. 3518 (codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997)).

²⁸⁷ Kyle-Holmes interview, p. 5.

²⁸⁸ Ibid.

²⁸⁹ Chang interview, p. 8.

²⁹⁰ Ibid.

²⁸² Ibid.

²⁸³ Ibid.

²⁸⁴ Region IX covers Arizona, California, Hawaii, Nevada, Guam, the Pacific Islands, and American Samoa.

staff did not conduct any full-scope reviews in FY 1998, or FY 1996 and 1997.²⁹¹

Complaint Investigations

Planning and Priorities

In its 1993 evaluation of OCR's activities, the HHS Civil Rights Review Team indicated that OCR complaint investigations were replete with problems, ranging from an overemphasis on following the same procedures regardless of the nature of the complaint, to inconsistent investigative efforts due to a lack of staff training on investigative procedures, civil rights law, and HHS policy. The large complaint inventory at that time resulted in considerable pressure to close cases, increasing the likelihood of cases being closed prematurely.²⁹²

Overall, although complaint investigation takes up the majority of OCR resources, the office is not keeping up with the inflow of complaints.²⁹³ Since 1994 OCR has taken steps to expedite its case handling by streamlining its complaint processing procedures and by instituting a high-priority case process.²⁹⁴ OCR is using team approaches, informal resolution processes (alternative dispute resolution techniques), and case prioritization to reduce the amount of time spent on complaints that are not likely to result in a finding of discrimination and to spend more resources on resolving "high impact problems of discrimination."²⁹⁵ Under its strategic plan, OCR also revised its *Investigative Procedures Manual* to reflect the "best practices" identified at headquarters and regional pilot projects on case management.²⁹⁶ However, the CRM does not contain a section on "best practices."

²⁹¹ The lack of funds and poor management could partially explain why more time is spent conducting limited-scope reviews. The regional manager has indicated that, historically, Region II has had difficulty maintaining stability and it is also a tough region to manage. There has been a high turnover of staff; currently there are five employees, and there also have been constant reductions in resources. Carter interview, p. 3.

²⁹² HHS, Civil Rights Review Team Report, pp. 6-7.

²⁹³ Although the complaint workload has decreased in recent years, it remains high. Numerous complaints remaining open are carried in from previous years.

²⁹⁴ USCCR, *Federal Title VI Enforcement*, p. 230.

²⁹⁵ *Ibid.*

²⁹⁶ *Ibid.*

Complaint Procedures

DOJ's coordination regulations require Federal agencies to publish procedures for handling complaints. The agencies should investigate all complaints with apparent merit and provide written notice to the complainant and the applicant or recipient of the disposition of the complaint. Agencies can allow recipients to investigate complaints against them, but they must ensure that the recipients have adequate complaint processing procedures and receive reports on complaint investigations from the recipients. Agencies and recipients must maintain a log of all complaints filed against them.²⁹⁷

OCR's *Case Resolution Manual* discusses three elements of the complaint investigation procedures: (1) evaluating the complaint, (2) attempting to resolve the complaint, and (3) securing compliance.²⁹⁸

Evaluating the Complaint

The CRM states that "a variety of methods may be used to facilitate" the complaints process.²⁹⁹ These include the "use of case triage, staffing and the team approach where appropriate."³⁰⁰ The CRM identifies 10 steps in the process of evaluating the complaint, including acknowledging the complaint, gathering basic information, making jurisdictional decisions, and prioritizing cases.³⁰¹

OCR staff begin the process of evaluating a complaint by determining whether an allegation it receives can be considered a complaint, as defined by OCR. OCR's definition of a complaint is "a written statement to HHS alleging that the rights of one or more persons have been violated and requesting, directly or by implication, that HHS take action."³⁰² It is unclear what the term "by implication" means, and some examples of what is and is not a complaint may be helpful here.

OCR states that oral allegations, anonymous correspondence, and inquiries seeking advice or information but no action or intervention from

²⁹⁷ 28 C.F.R. § 42.408 (1998).

²⁹⁸ OCR, CRM, table of contents.

²⁹⁹ *Ibid.*, p. 1.

³⁰⁰ *Ibid.*

³⁰¹ *Ibid.*, pp. 1-10.

³⁰² *Ibid.*, p. 1.

the Department do not qualify as complaints.³⁰³ However, this part of the guidance appears somewhat unrealistic and abstract because many people who call seeking advice probably will not know whether they would like intervention by OCR or from another agency since they probably will not be familiar with the workings of the Federal bureaucracy. The investigator will have to make that assessment. Here also, some illustrative "real-world" examples may be helpful so that staff will have guidelines on how to explain the formal complaint procedures to persons who call for information.

OCR currently does not require regional legal staff to work with investigative staff on every complaint intake procedure.³⁰⁴ According to one regional attorney, legal staff in his region have input on only about 20 percent of cases.³⁰⁵ This regional attorney has stated that he believes the expertise of legal staff could be very effective as a means of further streamlining OCR's approach to complaint processing.³⁰⁶ He stated that legal staff could help to reduce man hours in conducting complaints intake by relying as much as possible on a team approach using both legal and EOS staff.³⁰⁷ Such an approach could enhance the effectiveness of intake procedures because equal opportunity specialists "typically have more limited knowledge than attorneys do in determining if a case should be moot or if it has merit."³⁰⁸ This attorney stated that he would prefer (even though "the program people feel it is not necessary in most cases") that legal staff have more input during the complaint intake stage rather than have the EOS staff handle this matter on their own.³⁰⁹ He said that he never knows if certain cases that were dismissed by the EOS staff could actually have had issues under HHS' jurisdiction.³¹⁰ In addition, attorneys can help "clarify allegations, make EOS' initial assessment efforts more global and more fo-

cus, and expedite the overall intake process."³¹¹

Following its sections on receiving complaints and determining whether they are within the scope of OCR's jurisdiction, the discussion on evaluating complaints addresses gathering basic information. In this section, OCR identifies a list of documents and other information needed to conduct a thorough investigation. However, some of the items on the list would be more instructive and more useful as guidance if they were clearer and provided illustrative examples. For instance, one item on the list states that staff must obtain "sufficient information to understand the factual bases for the complainant's belief that discrimination has occurred and the basis of that discrimination."³¹² This item begs the question of what OCR considers "sufficient." Here again, examples comparing fact patterns and evidence gathered in several different cases are needed to illustrate clearly what kinds of information and how much of it is required to make a case under different theories of discrimination.

The list of basic information contains six items altogether. These range from simple requests such as identification of the complainant to much more extensive requests such as "sufficient information to understand the factual bases" and the "harm/damage that has occurred and what remedies/relief are being sought by the complainant."³¹³ The CRM states that OCR will only initiate complaint resolution procedures for those allegations for which "sufficient" information is provided. If such information is missing, OCR must notify the complainant by telephone or letter, and the complainant must then provide the required information within 15 days of the date of the request. If the complainant fails to provide the information, and OCR does not grant an extension, "the complaint will be closed and the complainant will be so informed."³¹⁴

This 15 calendar day requirement seems an onerous burden to place on the potential complainant both with respect to the brevity of time allotted and the sanction for not complying fully in that time. First, some of the language on

³⁰³ Ibid., p. 3.

³⁰⁴ Freeman interview, p. 7.

³⁰⁵ Ibid.

³⁰⁶ Ibid.

³⁰⁷ Ibid., pp. 7-8.

³⁰⁸ Ibid., p. 7.

³⁰⁹ Ibid.

³¹⁰ Ibid.

³¹¹ Ibid.

³¹² OCR, CRM, p. 3.

³¹³ Ibid.

³¹⁴ Ibid.

which the information request is based is somewhat technical and may not be understood fully by the layperson. For example, the potential complainant may not be aware of the “remedies/relief” available to him or her. Second, the complainant is not in the role of a private plaintiff who must establish her own case based on a legal cause of action. Rather, it is OCR that must address complaints in its capacity as a civil rights enforcement agency. It also is OCR that has the responsibility of investigating complaints to ensure compliance with the statute. Moreover, it is OCR EOS staff who are the professional investigators and, thus, should know exactly what kind of information they need to begin the investigation. Therefore OCR should be working with the complainant either by telephone or in person to gather the necessary information within a reasonable timeframe, without strict adherence to an arbitrary deadline.

In addition, the CRM states that OCR will only initiate complaint resolution procedures for those allegations for which “sufficient” information is provided. This is a very subjective term, yet the CRM does not provide any guidance to potential complainants on what constitutes “sufficient” information. The complainant therefore does not know how much information he or she must provide in order for their allegation to contain “sufficient” information. At a minimum, OCR should extend the 15-day deadline for those complainants who do not provide all the desired information on the first try.

The sanction of completely dismissing the complaint for failure to meet the 15 day deadline is certainly inappropriate and highly inefficient, particularly if OCR’s goal is to ensure universal compliance with civil rights laws. This very short period of time between the date of the notification letter and outright rejection of the complaint surely must eliminate a great many legitimate complaints that could help OCR to uncover noncompliance at the individual, small group, and systemic level. It also must significantly diminish OCR’s chances of being an effective civil rights enforcement agency.

At a minimum, OCR must revise its policy to extend the deadline to at least 30 days. DOJ/CORS investigative manual states clearly that “[y]ou should give the complaint a specific deadline by which the requested information should be submitted, *generally 30 days* from the

date of your written request, to complete a complaint.”³¹⁵ OCR also must revise its *Case Resolution Manual* to more clearly define the term “sufficient,” perhaps by listing the elements that are needed to provide OCR with information sufficient “to understand the factual bases for the complainant’s belief that discrimination has occurred and the basis of that discrimination.” Such a list would be for the benefit of both OCR staff and the potential complainant. This list might include the following:

- What occurred between you and the person you believe discriminated against you to give you this belief?
- When did these events occur (try to be as specific as possible and provide a date for each incident, if possible)?
- Why do you believe you were being discriminated against (the discrimination must have been because of your race, color, national origin/ethnicity, sex, disability, age)?
- Are there other people who were present when these events occurred who could attest to them (please provide names, addresses, and telephone numbers if possible)?
- How do you believe this situation should be resolved?
- What would you like OCR to do to resolve the situation?

Other key procedural guidance in the CRM’s discussion on evaluating complaints is the section on prioritizing cases. The primary objective of prioritizing cases, according to the CRM, is “to give OCR the management tool to target cases that are of significant national or local interest that raise key compliance issues.”³¹⁶ OCR’s guidance on prioritizing cases also states that OCR should take into consideration the available resources and the circumstances of the case when assigning a priority level. For example, the office should consider the relationship of the case to the overall workload and the annual operating plan of the regional office.³¹⁷

³¹⁵ DOJ, *Title VI Investigative Procedures Manual*, p. 20 (emphasis added).

³¹⁶ OCR, CRM, p. 6.

³¹⁷ *Ibid.*, pp. 6–7.

Once prioritized, a case will occupy one of three categories.³¹⁸ Category A, "National/Legal Significance; Potential Violations," contains cases that: (1) are of significant national or local interest; (2) will probably result in a finding of violation; or (3) will result in irreparable harm without expedited processing. Category B, "Complaints Requiring Additional Information," includes cases that have merit, but that require additional evidence to determine the extent to which further investigation will uncover a violation. Category C, "Complaints Suitable for Closure," covers cases for which there is sufficient information to conclude that further investigation will probably not result in a finding of violation.³¹⁹

Several issues relating to OCR's complaints prioritization or categorization procedures appear evident based on the Commission's evaluation. First, although OCR should utilize investigative staff to make an initial determination of which category a complaint should be in, OCR must ensure that the categorization of charges is reviewed by supervisors and attorneys after the interview to ensure that the correct category has been assigned. Currently, this is not the procedure in most regions as several regional attorneys have told the Commission that they generally are not involved in intake procedures. In light of this and also given that the categorization procedures are fairly new, it may be beneficial for the Office of Program Operations to conduct a quality assurance review of all the regional offices. This review could be based on a comparative sample of offices to assess how well offices are doing with the categorization procedures currently in place. Additional training could be provided to those offices where OPO determines there is a problem with correct charge categorization. OCR could also develop a plan to standardize and systematize a team approach across the regions. This plan could ensure that investigative staff and legal staff work closely in a more structured way to ensure proper handling of complaints.

Second, these procedures may be misunderstood by recipients, complainants, and other individuals outside OCR. Complainants may not understand clearly the prioritization system and

whether they can influence the decision process. Moreover, complainants may not know how to frame their complaint so that the important facts are made clear. Similarly, intake personnel may not be able to determine if there are bases for discrimination other than those described by the charging party.

Overall, the CRM's discussion on evaluating complaints, perhaps the single most important aspect of conducting complaint investigations, reveals some major weaknesses both in the guidance itself and some of the procedural requirements it outlines. One of the major problems is the 15-day limit placed on the complainant to respond to OCR's information request letter. This time limit places an onerous burden on the complainant to provide information, the exact nature of which OCR has not clearly identified. Moreover, the sanction of dismissing the complaint if the information is not received in 15 days is unfair and inconsistent with the objectives of ensuring universal compliance with and conducting vigorous enforcement of Federal civil rights laws.

In addition, the CRM's discussion on evaluating complaints contains numerous ambiguities and omissions. The various examples of ambiguity and lack of detail noted above are minor in and of themselves. However, taken together, these examples and others noted throughout this discussion indicate that OCR perhaps has taken its streamlining approach to an extreme that has rendered the document inadequate as procedural guidance for conducting complaint investigations. It is clear from interviews with regional investigative and managerial staff that the CRM generally can only be used as a supplemental desk reference, in tandem with other guidance.³²⁰ However, the CRM is the most important procedural guidance OCR develops for conducting complaint investigations. It should be able to stand alone as a source for information on complaint investigation procedures.

Resolving the Complaint

The next major discussion in the CRM addresses procedures for completing the investigation and resolving the complaint. This discussion

³¹⁸ Ibid., p. 7.

³¹⁹ Ibid.

³²⁰ Kyle-Holmes interview, p. 4 (noting that the CRM must be used in connection with other policies, regulations, and resources pertaining to investigative work); OCR Region VII EOS interview, p. 6.

opens with a listing of the many alternative dispute resolution (ADR) strategies OCR uses to resolve complaints. These include:

- Early complaint resolution.
- Factfinding conference.
- Mediation.
- Early neutral evaluation.
- OCR-initiated predetermination resolution negotiation.
- Preliminary or indepth investigation of the issues.
- Preliminary or final release of investigative findings.
- Postviolation letter of findings (LOF) negotiations and enforcement.³²¹

Interestingly, OCR lists “preliminary or in-depth investigation of the issues” as *one of* the alternative dispute resolution tools, which it is not. In-depth investigation of the issues is the traditional method of civil rights and other kinds of enforcement operations. It seems oddly incongruous for this kind of investigation to be listed along with methods that are alternative means of resolving complaints.

Based on a review of the CRM, the extent to which OCR has deemphasized traditional investigative work and other tasks associated with it seems excessive and is cause for concern. The CRM explains with regard to this list that “[a]ny approach, or combination of approaches, may be initiated at any time after receipt of the complaint and multiple approaches may be used to resolve any case.”³²² However, the CRM states in the next paragraph that general guidelines for specific investigatory procedures are set forth at Tab B. The main discussion then moves on to address other issues, including a section on use of alternative methods of case resolution, while relegating its discussion of investigative procedures to an appendix. It appears that, even in the way the CRM is structured, its emphasis is on alternative dispute resolution and away from indepth investigation.

Other guidance in the CRM tends to deemphasize the need to conduct thorough investigations as well. For example, in the section on using alternative methods to achieve case resolu-

tion OCR refers to “minimizing unnecessary investigative work by identifying key facts that are not in dispute.”³²³ This statement is made in the context of describing the factfinding conference as a tool for facilitating case resolution. However, nowhere does the guidance state that this method probably should not be used without independent corroboration from OCR’s own investigative work.

Elsewhere, the guidance states that “in some cases it will be helpful to prepare an investigative report (IR).” It describes the investigative report as a written document that contains the following: the allegations investigated in a case, the legal standards applicable to those allegations, a summary and analysis of the information discovered during the investigation, the findings of fact and the conclusions of law OCR draws from that information, and any recommendations for further action.³²⁴ All of this information seems to be the exact information OCR would want to retain for *every* complaint it investigates. Yet the CRM states only that an IR may sometimes be “helpful.”³²⁵ By preparing this information for every case, OCR can maintain a more complete record of every recipient investigated. It can also continue to ensure that the skills of staff in writing analyses of its cases do not diminish as a result of never having to prepare letters of finding.

Although the Commission commends OCR for its effort to resolve complaints through alternative dispute methods, OCR appears to rely too heavily on alternative dispute resolution. This break with traditional investigative procedures may be creating an unintentional erosion of investigative technique and capability. Two similar alternative dispute resolution tools, early complaint resolution (ECR) and predetermination settlements, provide examples of some potential negative consequences. Both of these processes involve negotiating with the recipient and attempting to close the case before making any actual findings as to violations. According to the *Case Resolution Manual*, ECR “facilitates the resolution of complaints by providing the parties involved the opportunity to resolve the

³²¹ OCR, CRM, p. 11.

³²² *Ibid.*

³²³ *Ibid.*, p. 14.

³²⁴ *Ibid.*, p. 15.

³²⁵ *Ibid.*

allegations prompting the complaint.”³²⁶ In early complaint resolution, OCR apparently assumes the somewhat neutral role of facilitator, assisting the parties in reaching a settlement. However, if a settlement results, OCR does not approve it, nor does OCR conduct any monitoring of the agreement. It merely informs the parties that the complainant has the right to file another complaint if the recipient fails to abide by the agreement.³²⁷ Unlike ECR, predetermination settlement negotiations are initiated and conducted by OCR. Although the CRM’s description of the predetermination settlement process lacks detail, it appears that OCR would approve and monitor any agreements reached.

Although in principle ECR seems an economical and expedient approach to resolving disputes, there are a number of potential problems with it. First, the CRM is unclear about what OCR’s role as facilitator actually entails. If OCR is not actively representing the complainant during the negotiations, an imbalance of power in favor of the recipient will, in many cases, result. OCR’s responsibility for enforcing the complainant’s rights does not disappear simply because it acts as facilitator and does not approve any resulting settlement agreement. The CRM should make clear to prospective investigators OCR’s continuing relationship with the complainant. This relationship endures until the case resolution letter documenting the agreement is sent to the parties. Second, for OCR to determine that no monitoring at all is necessary and, in the case that the recipient should fail to comply with the agreement, to leave the complainant with no other remedy than to file another complaint, is entirely inefficient as a means of ensuring compliance. Without any means of ensuring continued compliance, OCR essentially leaves the complainant in the same situation he or she would have been in had he or she not filed a complaint in the first place.

Two additional negative effects of ECR on the effectiveness and efficiency of investigations may also occur in the context of predetermination settlements. First, neither ECR nor predetermination settlement requires the investigator to write a letter of finding. The potential loss of

skill for investigative staff in this area has been suggested by a regional OCR attorney. According to one regional attorney, the agency’s emphasis in recent years has been on “predetermination settlements.”³²⁸ In preparing case resolution letters based on such settlements, OCR investigators do not have to develop findings that explain the violations.³²⁹ They merely have to state the terms of the settlement and explain the basis for OCR. According to this attorney, “In recent years the emphasis on predetermination settlement has been so great that the number of violation letters that are detailed and coherent is down.”³³⁰ Without writing investigative reports or developing findings, OCR investigative staff have little reason to learn, use, or hone their investigative skills. This devolution of standards for conducting investigations and developing documents detailing the specific deficiencies found, regardless of whether there is a settlement agreement, is an unfortunate side-effect of the emphasis on these kinds of resolutions.

Second, the agency’s “very strong preference for predetermination settlements”³³¹ could create a tendency on the part of investigators to attempt to resolve cases prematurely. This incentive for early settlement could, in turn, have two dangerous effects. First, the individual complainant is in the vulnerable position of trusting the investigator’s judgment as to when settlement is appropriate. An investigator might be more inclined to overlook details associated with the complainant’s situation that would make settlement problematic. Second, early settlement runs the risk of missing patterns in the policies, procedures, and practices of the recipient that indicate systemic discrimination. Since ensuring system compliance is one of OCR’s priorities, the CRM should include case closure protocols that require investigators to do a “compliance feasibility analysis.” The analysis would assess whether the circumstances surrounding the complaint suggest pervasive, institutional discriminatory practices, complex or novel questions of law or fact, or other conditions that could result in a disparate impact on a large number of beneficiaries. If any of these conditions are pres-

³²⁶ *Ibid.*, p. 13.

³²⁷ *Ibid.*, p. 15.

³²⁸ Graham interview, p. 20.

³²⁹ See OCR, CRM, pp. 15–16.

³³⁰ Graham interview, p. 22.

³³¹ *Ibid.*, p. 20.

ent, then the case should not be closed, but expanded into a systemic compliance review. The individual whose complaint triggered the review should have the option of settling early or waiting for the outcome of the compliance review.

The final section of the discussion on attempting to resolve the complaint is on monitoring. This is an extremely important aspect not only of complaint (and compliance review) resolution, but also the most important element in ensuring that compliance is maintained among recipients long after the complaint investigation or compliance review has ended. The CRM, however, gives its section on effective monitoring implementation short shrift. It mentions that "monitoring is critical to ensure that all necessary action is completed."³³² It also states that "whenever appropriate, OCR should keep in touch with the recipient, the complainant and any other pertinent parties" and "monitoring may or may not require an on-site visit."³³³

However, the discussion does not provide the degree of emphasis on monitoring activity that it would have if it were more in depth. Statements such as "[w]henver appropriate, OCR should keep in touch"³³⁴ and "[m]onitoring may or may not require an on-site visit"³³⁵ seem far too tepid to carry with them the message that OCR is intent on performing vigorous monitoring activities. The CRM discussion on monitoring should go beyond the general statements it makes to offer specific examples of monitoring activities appropriate for different kinds of compliance agreements. For example, OCR has placed a significant amount of emphasis in recent years on the LEP issue. The CRM discussion might address effective means of ensuring that a recipient that has agreed to develop a policy on LEP actually follows through on developing that policy. More importantly, OCR must ensure that such a recipient *actually implements* that policy. Based on the Commission's evaluation of OCR's procedures for ensuring compliance, it is unclear to what extent OCR is capable of providing the kind of effective monitoring to ensure that recipients are following through with the agreements they are making with OCR. At a mini-

³³² OCR, CRM, p. 17.

³³³ Ibid., pp. 17-18.

³³⁴ Ibid., 18.

³³⁵ Ibid., p. 17.

num, it seems necessary for OCR to conduct some form of onsite monitoring activity for *all* recipients that have been subjected to a compliance review or complaint investigation.

According to staff in Region IV, complaint investigations often are limited by resources. For example, a complaint that was filed in 1998 was not scheduled to be investigated until May 1999 because travel funds were not available in 1998.³³⁶ The EOS noted that the decision to follow through or complete a complaint depends on the backlog during that year and what is already on the docket for reviews. These conditions can postpone an investigation until the next fiscal year.³³⁷

Analysis of OCR's Case Processing Database: Complaints

HHS civil rights enforcement activities were once complaint driven. During the late 1980s and into the early 1990s, the number of complaints increased each year, taking most of OCR resources.³³⁸ OCR's complaint workload reached an all-time high of 2,666 complaints in FY 1996. Then, as shown in figure 4.6, between FY 1996 and 1998 the complaint workload decreased, by approximately 10 percent each fiscal year, yet remained high.³³⁹

Although, there is no one explanation for the continuous decline in OCR's complaint workload, between fiscal years 1996 and 1998, one of the reasons that has been cited is that current discrimination is more subtle and individuals are less aware of their rights, particularly in the health services area.³⁴⁰ Other possible reasons for decreases in the complaint workload during

³³⁶ OCR Region IV EOS interview, p. 5.

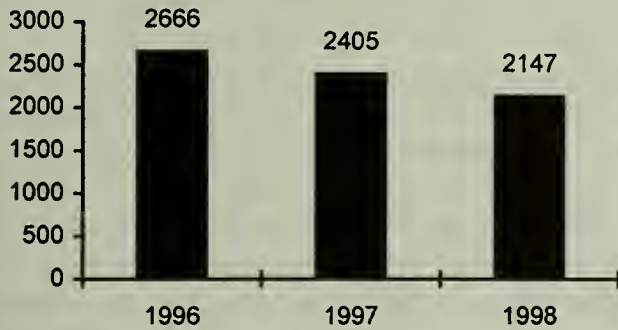
³³⁷ Ibid.

³³⁸ USCCR, *Funding Federal Civil Rights Enforcement*, p. 229.

³³⁹ OCR, CATS Database. In June 1999, OCR informed the Commission that its latest data for FY 1999 indicated a reversal from the 2-year decline in complaint receipts. OCR stated that it received 29.3 percent more complaints this fiscal year through April 30 (1,158), than had been received last year as of the same time. Based on projecting average monthly receipts during the first 7 months of FY 1999 through the remainder of the fiscal year, OCR could receive nearly 2,000 complaints this fiscal year, an increase of 28 percent above FY 1998. Perez letter, June 3, 1999, enclosure, "Commission on Civil Rights Evaluation of HHS OCR Headquarters Follow-up Questions," p. 11, item 23.

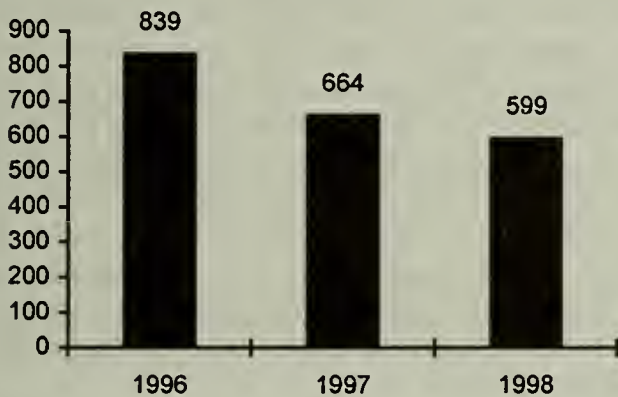
³⁴⁰ Rhinehart interview, p. 1-2.

Figure 4.6
OCR's Total Complaint Workload, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

Figure 4.7
OCR's Total Complaints Carried-in from Previous Fiscal Year, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

FY 1996 through FY 1998 are that OCR streamlined its complaint processing by issuing the *Case Resolution Manual*, implemented a triage system for handling complaints, and developed a team concept as a means for processing complaints and alleviating backlogs.³⁴¹

The total complaint workload of OCR consists of those complaints received in the current fiscal year and those carried into the current fiscal year from the previous year. Between FY 1996 and 1998, the number of complaints carried in from the previous years continuously declined

(figure 4.7). Also during this time, the percentage of closed carry-in complaints increased and the percentage of investigated carry-ins decreased. For example, in FY 1998, 599 complaints were carry-ins from FY 1997; 82 percent of these carry-ins were closed, with only 61 percent of these complaints being investigated. At the end of FY 1998, 110 complaints that were carry-ins from FY 1997 were still open.³⁴²

The prioritizing of complaints may be a contributing factor in the decreases in the total number of open complaints since FY 1996. As the total number of open complaints is decreasing, the total number of closed complaints also is decreasing. Between the end of FY 1996 and FY 1997, the number of open complaints decreased by 9.7 percent, and between FY 1997 and FY 1998 the number of open complaints decreased by 16 percent. In FY 1998, only 503 complaints remained open at the end of the fiscal year (figure 4.8). OCR estimated that it intended to investigate 415 or 82.5 percent of these open complaints.³⁴³

Because open complaints become the carry-ins for the next fiscal year, it is to OCR's advantage to resolve as many complaints as possible to alleviate any backlogs. In FY 1992, OCR had 1,230 complaints unresolved at the end of the year.³⁴⁴ For FY 1999, only 503 unresolved complaints were carried-in from FY 1998. At the national level this figure seems small; however, nearly half of these complaints are in only two regions, Region IV and Region IX.³⁴⁵

Some of OCR's regional offices appear to be more efficient than others in terms of handling complaints. The lack of resources, such as staff, and the high volume of pregrant award reviews deem it impossible for regional offices to alleviate their backlog of complaints. At the end of FY 1998 all regions had unresolved complaints that would be carried into FY 1999 (figure 4.9). Forty-two percent of all complaints that remained open

³⁴² OCR, CATS Database. Comparatively, in FY 1997, OCR closed 71 percent of the complaints carried-in from FY 1996 and investigated 66 percent of the closed complaints. In FY 1996, OCR closed 70 percent of the complaints carried-in from FY 1995 and investigated 68 percent of those closed complaints. Ibid.

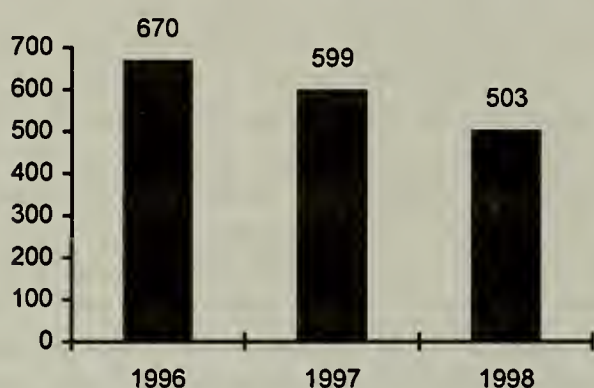
³⁴³ Ibid.

³⁴⁴ USCCR, *Funding Federal Civil Rights Enforcement*, p. 229.

³⁴⁵ OCR, CATS Database.

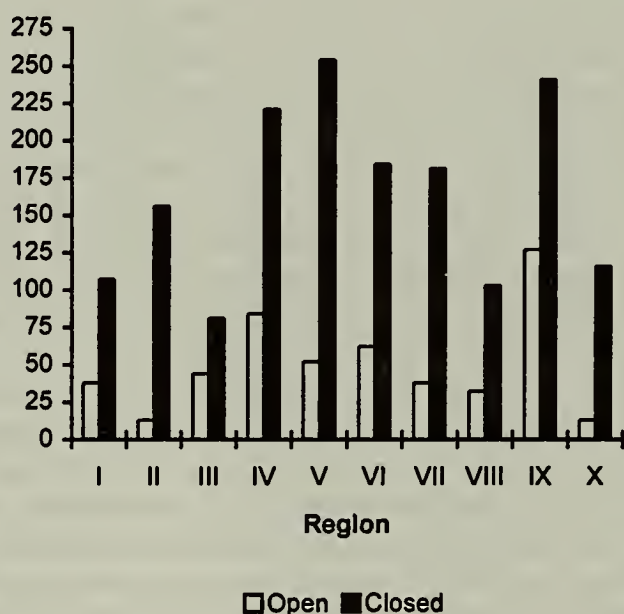
³⁴¹ OPO interview, p. 27 (statement of Mackey).

Figure 4.8
OCR's Total Open Complaints, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

Figure 4.9
OCR's Open and Closed Complaints by Region, FY 1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

at the end of FY 1998 were in Regions IV and IX. Region IV has the largest total workload of all the regions, but they also had the largest compliance staff, 19 individuals, in comparison to the other regions.³⁴⁶ The majority of Region IV's workload consists of pregrant award reviews, not complaints (table 4.2). Comparatively, Region IX has a compliance staff of only 9 individuals and a smaller workload than Region IV. It appears that as the regions have more pregrant award reviews to conduct, they are less likely to be able to efficiently handle their complaints, allowing them to alleviate backlogs. OCR has attempted to address the problem of complaint backlogs by developing its prioritization process to ensure that the regions are "moving through their caseload and their case docket in a fairly expeditious manner in terms of moving complaints along and not letting them languish in noninvestigative stages or getting bogged down in particular stages of the investigation."³⁴⁷

Regions II and X each had only 13 unresolved complaints at the end of FY 1998. Region II is more complaint driven than any of the other OCR regions,³⁴⁸ and its total workload and compliance staff are smaller than those of the other regions. Although Regions II and X have backlogs, for the most part they are able to resolve their cases in a timely fashion. In FY 1998, Region II closed all of its carry-in complaints from FY 1997. In both FY 1997 and 1998, Region X closed all complaints that were carry-ins from previous years.³⁴⁹

The number of complaints OCR receives and closes does not reflect its investigation workload, because OCR does not investigate all complaints it receives.³⁵⁰ As shown in table 4.2, the complaint investigations workload has increased consistently over the past three fiscal years. Between FY 1996 and FY 1998 OCR more than

³⁴⁶ OCR, Regions I–X, FY 1998 AOP, table D.

³⁴⁷ OPO interview, p. 38 (statement of Mackey).

³⁴⁸ See app. 4.1.

³⁴⁹ Region X also tends to work with Region IX by conducting some of Region IX's pregrant award review work. Pollock interview, p. 3. Region X has cited its team approach as the vehicle that enables it to close most of its cases in less than 6 months. OCR Region X EOS interview, p. 10.

³⁵⁰ There are a number of reasons why OCR does not conduct investigations for every complaint it receives. For example, in some instances, complaints are not investigated if it is determined that OCR does not have jurisdiction.

doubled the number of investigations they did. However, because investigations do not account for the entire complaint workload, OCR still does not close (through investigations or other clo-

Findings, Deficiencies, Remedies, and Sanctions

DOJ's coordination regulations direct agencies to initiate "appropriate enforcement proce-

Table 4.2
OCR's Regional Workload, FY 1998

OCR region	Total workload	Complaints	Pregrants	Other activities*
I	551	25.8	37.6	36.6
II	345	55.9	21.7	22.4
III	423	25.5	59.8	14.7
IV	1,419	19.2	70.7	10.1
V	1,085	27.2	51.7	21.1
VI	1,293	18.8	66.4	14.8
VII	596	29.2	61.2	9.6
VIII	339	37.5	46.6	15.9
IX	931	37.3	60.2	2.5
X	403	37.2	34.5	28.3

* The other enforcement activities identified by OCR are compliance reviews, monitoring, and technical assistance.

SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, FY 1998 Annual Operating Plans, Regions I-X, Table D.

Table 4.3
OCR's Investigations, FY 1996-1998

Investigations	FY 1996	FY 1997	FY 1998	Change FY 1996-97	Change FY 1997-98
Carry-ins	19	24	44	26.3%	83.3%
New starts	43	78	90	81.4%	15.4%
Closed	36	58	71	61.1%	22.4%
Open	26	44	63	69.2%	43.2%
Total workload	62	102	134	39.2%	31.4%

SOURCE: Thomas Perez, director, Office for Civil Rights, U.S. Department of Health and Human Services, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, U.S. Commission on Civil Rights, July 7, 1999 (re: health care report), addendum, p. 6.

tures) every complaint it receives by the end of the fiscal year.³⁵¹

³⁵¹ For example, OCR informed the Commission that at the close of FY 1998 its ending inventory of complaints was 23.4 percent of its total complaint workload for the year. OCR noted that this represents an improvement over FY 1992 where the ending inventory represented 37.5 percent of the total annual workload. Clearly, OCR is doing a better job of keeping on top of its complaint workload. However, almost one-quarter of OCR's complaints still remain open at the end of the fiscal year. Thomas Perez, director, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil

dures" against recipients who have been found in noncompliance and who do not enter into compliance voluntarily.³⁵² The "Guidelines for the Enforcement of Title VI, Civil Rights Act of 1964"³⁵³ specify courses of action a Federal

Rights Evaluation, U.S. Commission Civil Rights, July 7, 1999, (re: health care report), addendum, pp. 6-7.

³⁵² 28 C.F.R. § 42.411(a) (1998).

³⁵³ 28 C.F.R. § 50.3 (1998).

agency can take when it cannot achieve voluntary compliance. They require agencies, before taking the ultimate sanction of terminating Federal financial assistance, to consider taking available alternative actions such as: (1) seeking court enforcement, (2) seeking the assistance of other Federal agencies or State and local government agencies with authority to enforce non-discrimination requirements, and (3) bypassing recalcitrant State recipients by awarding assistance to local governments or directly to the beneficiaries.³⁵⁴ They also specify that a Federal agency can defer financial assistance temporarily. The guidelines outline procedures to be followed for new applications, requests for continuation or renewal of assistance, short-term programs, and subgrantees.³⁵⁵

OCR compliance reviews and complaint investigations that result in a finding of noncompliance often are resolved through corrective action commitments on the part of recipients, rather than through administrative or legal proceedings.³⁵⁶ The vast majority of cases in which OCR makes findings of violations are resolved through some form of negotiated settlement.³⁵⁷

Securing Compliance

The CRM discussion on securing compliance where predetermination resolution fails includes brief sections on issuing a “violation letter of findings” and conducting negotiations.³⁵⁸ These sections provide general procedural information. For example, the section on issuing a violation letter of findings states that it should be prepared when an investigation establishes that there is a violation and a predetermination resolution proves unsuccessful.³⁵⁹

The CRM states that a violation LOF should contain the following elements:

- A statement of OCR’s jurisdictional authority, including recipient status and the statutory basis for the investigation.
- A statement of each issue, the findings for each, supported by any necessary explanation

or analysis of the information on which the findings are based, and of the applicable regulations.

- A description of what remedies the recipient must take to achieve voluntary compliance (a proposed corrective action agreement may be attached to the LOF for the recipient’s consideration and adoption).
- A notice of the time limit on OCR’s settlement process and the consequences of failure to achieve a voluntary settlement.³⁶⁰

The CRM includes the following guidance in its section on conducting negotiations:

Prior to the start of negotiations, the OCR team should develop strategies regarding the roles to be played by various members, appropriate remedies, timeframes for the completion of remedial steps and/or reporting requirements. Negotiations may include meetings, an exchange of letters and/or telephone calls. The complainant should be informed of OCR’s reasoning for the specific remedial actions required of the recipient and where appropriate, be given an opportunity to respond or offer alternative solutions. Records of contacts between and among parties should be maintained in the case file.³⁶¹

This guidance addresses negotiation techniques from a broad perspective, in keeping with OCR’s intention to make the CRM a more flexible, less prescriptive procedural manual. However, because of the importance OCR attaches to negotiating settlement and corrective action agreements with recipients for resolving cases, the discussion here should contain some illustrative examples for references it makes. For instance, the statements about developing “strategies regarding the roles played by various members, appropriate remedies,” etc., might be more useful to investigative staff as guidance and instruction if the CRM offered specific examples of how these techniques have been or can be used in various cases, real or hypothetical. Overall, this discussion on securing compliance suffers from the same lack of detail and helpful examples as does the rest of the manual.

³⁵⁴ *Id.*, note I.

³⁵⁵ *Id.*, note II.

³⁵⁶ See USCCR, *Federal Title VI Enforcement*, p. 230.

³⁵⁷ Rhinehart interview, p. 13.

³⁵⁸ OCR, CRM, p. 19.

³⁵⁹ *Ibid.*

³⁶⁰ *Ibid.*

³⁶¹ *Ibid.*

Compliance Review and Complaint Investigation Findings

In determining the results of its compliance reviews and complaint investigations, OCR applies the applicable legal and regulatory standards to investigative findings.³⁶² These results, and OCR's analysis are presented in OCR's case resolution letters and letters of finding (LOFs).³⁶³ Upon completion of its compliance reviews and complaint investigations, OCR sends the involved parties case closure letters, as well as copies of any associated settlement agreements. If the investigation originated with a complaint, the closure letter notifies the parties of the agency's findings with regard to each allegation.

Although the CRM's discussion of these documents is vague and fragmented, it appears that case resolution letters are intended to be concise documents that communicate the basic issues and outcomes associated with cases that close without a formal finding of violation.³⁶⁴ Case resolution letters are appropriate for cases settled through early complaint resolution or predetermination settlement, or uncomplicated cases in which no violation was found. The level of detail in the letter is up to the discretion of OCR staff, although it is suggested that staff weigh such factors as the scope of the violation, the length of plan implementation, the conduct of the recipient, and the recipient's or complainant's understanding of OCR's actions.³⁶⁵

In contrast with the case resolution letter, the LOF is a more formal, rigorous document that is

analogous to a court opinion.³⁶⁶ An LOF must always be issued when a violation is discovered and OCR is unable to resolve it through a predetermination settlement.³⁶⁷ Often, a "violation LOF" will include a proposed corrective action agreement as an enclosure.³⁶⁸ OCR then attempts to negotiate with the recipient to develop a corrective action letter or agreement.³⁶⁹ This document indicates that a violation was found, but that the recipient has committed in writing to some form of remediation.³⁷⁰ A "no violation LOF" is issued in cases that exhibit no legal basis for a violation, but OCR staff think that an LOF is required because of the complexity of the facts or because of the perceived significant precedential value of a case.³⁷¹

Compared with LOFs, the relative brevity of case resolution letters allows for the consumption of less drafting time in the short run. It could, however, affect investigators' efficiency and consistency: if the facts and legal standards are not included in a case resolution letter, it could render comparisons between factually similar cases more difficult. The process of comparing current cases with similar past cases facilitates an investigator's appreciation and comprehension of a new case. It affords the investigator a preexisting framework of issues and remedies that might be adapted to the new case. Such comparisons also guard against inconsistent findings. For the foregoing reasons it would benefit regional staff if OCR were to require legal and factual analysis in case resolution letters, as it requires in LOFs.

Because every recipient and complainant that have been involved in a complaint investigation or compliance review should be fully informed of OCR's determinations, OCR's case closure letters are the most important written contact between OCR, recipients, and complainants. The analyses

³⁶² The manual dictates that procedures for complaint resolution and enforcement be applied to compliance reviews, as appropriate. *Ibid.*, p. 22.

³⁶³ *See* *ibid.*, pp. 15–16. The term "case closure letters" will be used hereafter in reference to both types of letters.

³⁶⁴ *See* *ibid.*, § E (1). The CRM prescribes only that case resolution letters contain: (1) the basis for the complaint [or compliance review]; (2) a brief statement of the allegations [or in cases of compliance reviews, a statement of potential violations]; (3) a brief statement of OCR jurisdiction; (4) an explanation of the basis of OCR's determination that the case has been resolved; (5) a copy of any agreement, where appropriate; and (6) in the case of ECR, a statement that if a subsequent breach occurs, the case may be reopened by the filing of a complaint. In some cases, the letter may also include a summary of the pertinent legal standard, a brief statement of the facts, and an analysis thereof.

³⁶⁵ *Ibid.*

³⁶⁶ The LOF must contain: (1) a statement of OCR's jurisdiction; (2) a statement of each issue, along with corresponding findings supported by any necessary explanation or analysis; (3) a description of the remedies required for voluntary compliance by the recipient; and (4) a notice of the time limit for OCR's settlement process and the consequences of failure to achieve a voluntary settlement. *Ibid.*, p. 19, § III (A).

³⁶⁷ *Ibid.*

³⁶⁸ *Ibid.*, p. 19.

³⁶⁹ *Ibid.* *See also* *ibid.*, p. 12, § II (5).

³⁷⁰ *Ibid.*, p. 12, § II (5).

³⁷¹ *Ibid.*, p. 16.

of compliance standards enunciated in them must be thorough and clear. Moreover, these letters must contain an accurate and complete description of the OCR investigation. They should serve as important indicators of the quality and efficiency of OCR's investigative process both for what they reveal about the thoroughness of OCR's investigations, as well as the depth and detail of the letters themselves.

The importance of case closure letters and other documents indicates the need for the implementation of standardized, written quality assurance measures that include, at a minimum, legal and managerial review of every closure document, regardless of whether there is a finding of a violation. OCR's credibility with HHS funding recipients, beneficiaries, participants, the Department of Justice's Coordination and Review Section, and other civil rights enforcement agencies, depends in part on the quality of these letters. However, the extent to which letters of finding and other case closure documents are reviewed by attorneys varies from region to region. Several regional civil rights attorneys said that they usually review cases only when there is a finding of a violation or when the issues addressed are particularly difficult, important, or novel.³⁷² At least one attorney, however, believes that a review by legal staff is necessary since many LOFs contain "legal discussions" and it is impossible to know the extent to which a legal review of an LOF is needed unless one is conducted.³⁷³ Recognizing the significant downsizing OCR has undergone over the past 20 years, it may be very difficult for OCR to develop and implement a quality assurance procedure whereby every case closure letter is reviewed by a regional attorney as well as the regional manager. However, a task force to address the issue may be an effective means of finding ways to upgrade OCR's current quality assurance measures for case closure letters and other documents.

One senior attorney in the Office of General Counsel's Civil Rights Division at HHS has stated that he believes staff have improved the

³⁷² See Ellen Miyasato, civil rights attorney, Region X, Office of the General Counsel, HHS, telephone interview, Feb. 2, 1999, p. 3 (hereafter cited as Miyasato interview); Rhinehart interview, p. 5; Freeman interview, p. 8; Graham interview, p. 3.

³⁷³ Freeman interview, p. 8.

quality of their compliance reviews and complaint investigations over the past few years.³⁷⁴ However, the Commission's review of OCR's case closure letters and other documents for cases completed during FY 1995–1998 indicates problems with the quality of the closure documents themselves, and suggests deficiencies in OCR's enforcement efforts as well. The case closure letters demonstrate the following inadequacies: (1) the lack of thoroughness and rigor in investigative technique and methodology, particularly a general failure to ascertain differences in the *quality* of health care provided across racial/ethnic lines; (2) the failure to identify and apply appropriate legal standards; (3) an inability to resolve and close cases on a timely basis; (4) inattention to title VI issues; and (5) a lack of effective monitoring techniques. A discussion analyzing several of these case closure letters illustrates the extent of the problems.³⁷⁵

Questionable Investigative Approach and Methodology in Case Closure Letters

The Commission's review of case closure letters and documents relating to title VI race discrimination claims indicates significant problems with OCR's investigative methods. In particular, individual letters show that the evidence on which OCR relies in determining the presence of discrimination often appears incomplete. Examples from OCR's recent case closure letters provide anecdotal evidence illustrating these problems.

Some OCR letters of finding indicate cursory investigations with limited application of investigative techniques crucial in making accurate determinations of compliance.³⁷⁶ For example,

³⁷⁴ OGC interview, p. 9 (transcript).

³⁷⁵ The Commission's evaluation of these documents is qualified by one caveat: because of the "nonprescriptive" nature of the CRM and its consequent ambiguity with regard to the description, utilization, and required elements of the case closure letters, it is uncertain whether any particular letter that found no violation actually reflected all the investigative efforts undertaken by OCR regional staff.

³⁷⁶ See Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, letter to Robert Ladenburger, president and chief executive officer, St. Peter's Hospital, Helena, MT, Aug. 18, 1998 (re: #08963801) (hereafter cited as Kyle-Holmes, Aug. 18, 1998 letter, re: #08963801); Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, letter to Lorin C. Mackay, administrator, Teton Medical Center, Choteau, MT, Aug. 18, 1998 (re: #08963802) (hereafter cited as Kyle-Holmes, Aug. 18, 1998 letter, re: #08963802); Caroline

the descriptions of investigations provided in several case closure letters reveal no evidence that OCR examined appropriate documents or conducted interviews necessary to determine if a complaint allegation was true. In one letter documenting the closure of a complaint referred to OCR from HCFA, OCR addressed an allegation that a doctor had refused treatment to an emergency room patient in violation of the Hill-Burton Act and its implementing regulation.³⁷⁷ The letter states that HCFA investigators had already addressed the complaint, and that, according to HCFA, the recipient had since corrected its compliance deficiencies.³⁷⁸ OCR's determination that the deficiencies had been corrected appears based on nothing more than a review of policies and procedures that the hospital claimed it enforced. The letter merely states:

OCR reviewed the recipient's amended emergency room admission and transfer policies and procedures and found them to comply with Subpart G of the Hill-Burton regulation. The recipient has advised OCR that Subpart G Hill-Burton notices are posted in various areas of the facility including the admissions office, business office, and emergency room as required by 45 C.F.R. Part 124.604(a). . . . Based on the above, OCR concludes that the recipient is complying with the requirements of the regulations with regard to the specific issues discussed. Therefore, we have closed this complaint and take no further action in the matter.³⁷⁹

There is no evidence that OCR interviewed any staff or individuals in the service area who had

Chang, regional manager, Region I, OCR, HHS, letter to Donald Holl, president, Claremont, NH, Apr. 20, 1998 (re: complaint no. 01-97-3806) (hereafter cited as Chang letter, Apr. 20, 1998, re: complaint no. 01-97-3806); Caroline Chang, regional manager, Region I, OCR, HHS, letter to Robert Ingala, acting chief executive officer, Hale Hospital Haverhill, MA, Mar. 31, 1998 (re: complaint no. 01-98-3009); Caroline Chang, regional manager, Region I, OCR, HHS, letter to William Riordan, president/chief executive officer, St. Vincent's Medical Center, Bridgeport, CT, Apr. 20, 1998 (re: complaint no. 01-98-3014); Caroline Chang, regional manager, Region I, OCR, HHS, letter to Gary Daniels, president/chief executive officer, Penobscot Bay Medical Center, Rockport, ME, Aug. 7, 1998 (re: complaint no. 01-98-3063).

³⁷⁷ Chang letter, Apr. 20, 1998, re: complaint no. 01-97-3806, p. 1.

³⁷⁸ *Ibid.*

³⁷⁹ *Ibid.*

used the facility; nor is there any evidence that OCR conducted any form of onsite investigation.

Another aspect of OCR's investigative approach where the Commission observed problems is the application of both disparate treatment and disparate impact analysis. For example, in February 1998, OCR issued a letter of finding to a complainant in Ohio that indicates numerous mistakes in conducting these analyses.³⁸⁰ The complainant alleged that the recipient, a hospital, discriminated on the basis of race by refusing to provide psychiatric or substance abuse treatment to his daughter on an inpatient basis.³⁸¹ It appears from the letter of finding that OCR investigative staff failed to identify the appropriate standards or admission requirements for 24-hour-a-day confinement as an inpatient. In addition, the letter of finding indicates that the investigator failed to conduct a comparison with similarly situated patients of other racial backgrounds to assess thoroughly the possibility of discrimination arising from disparate treatment. In a similar vein, the letter of finding does not indicate whether OCR investigators made an appropriate comparison with similarly situated nonminority patients to determine whether self- or family reporting was a standard policy, used consistently without regard to race, by the chemical dependency unit in determining whether to admit patients.

This letter of finding appears to base part of its analysis on statistical data required to evaluate discrimination based on a disparate impact theory.³⁸² According to the letter, during the period from January 1996 to March 1997, 5 percent of the inpatients on the adolescent chemical dependency unit were African American.³⁸³ However, the letter of finding failed to indicate what percentage of minority or black patient "candidates" were rejected by the hospital versus nonminority or white patient candidates. In other words, the correct analysis for determining whether there was a disparate impact in this complaint was not applied, thus the finding of no cause is flawed in its basic premise. One OCR

³⁸⁰ Charlotte Irons, regional manager, Region V, OCR, HHS, letter to Marvin Parms, Stow Ohio, and Michael Bernatovicz, CEO, Barberton Citizens Hospital, Barberton, OH, Feb. 4, 1998 (re: docket no. 05973099).

³⁸¹ *Ibid.*, p. 1.

³⁸² *Ibid.*, p. 2.

³⁸³ *Ibid.*

regional attorney has indicated that he thinks OCR EOS staff do not have sufficient policy guidance on disparate impact analysis, and some investigators lack an overall clear understanding of how to conduct a disparate impact analysis.³⁸⁴

The Commission's review of OCR's letters of finding and other case closure documents also raised similar concerns with other procedures, such as interviewing medical professionals and investigating medical procedures, that are the basis for a complaint. For example, in November 1997, OCR issued a letter of finding to a complainant in Philadelphia, Pennsylvania, in a case in which the complainant alleged she had been discriminated against on the basis of national origin when a doctor informed her that he would not perform a specific medical procedure on her.³⁸⁵ In finding no evidence of discrimination in this case, OCR stated that "[w]hile it is not within OCR's purview to investigate either the appropriateness or quality of medical care given to a patient, it is within our authority to determine whether the provision or denial of services and/or treatment extended to a patient is on a nondiscriminatory basis."³⁸⁶ This statement simply may be poorly worded; however, it is counterintuitive for OCR to suggest that it can make the determination of whether care was provided on a nondiscriminatory basis without ever having to assess the appropriateness or quality of care, since these may be the very indicators of discriminatory treatment or impact.

The letter of finding contains little evidence that OCR investigated to determine whether there was discrimination with respect to specific procedures. It does appear that the medical records relating to the patient were reviewed.³⁸⁷ In addition, a physician on staff with the Public Health Service was consulted.³⁸⁸ However, there is no evidence from these findings that OCR

conducted an appropriate comparative analysis to determine whether similarly situated nonminority individuals were treated the same or differently with respect to the specific procedure and other treatment that may be relevant. It also appears that OCR did not do a thorough statistical analysis to determine whether a disparate impact based on national origin existed at the facility with respect to specific procedures. The only statistical analysis OCR presented was contained in a footnote that cited admissions statistics, stating that the recipient "admits more than 100 persons who identified themselves as being Hispanic."³⁸⁹ However, the complainant alleged that she was denied a *particular procedure*. Without more thorough investigation, OCR cannot ensure that all patients have access to high-quality care and the *same*, or substantially the same, quality of care, particularly with respect to specific procedures.

Another problem with OCR's investigative approach is that, in at least one case, a finding of compliance was predicated in part on the notion that because no other complaints or grievances had been filed against the recipient, this somehow helped to show that the recipient was in compliance with title VI. The case, which arose in Philadelphia, involved an allegation of differential treatment on the basis of race. OCR found that "the complainant and her family were not treated differently than others based upon their race or the disability of her son" because statistical analysis of the hospital's patient data "compares favorably with the number of Blacks living in Philadelphia county, as well as the Philadelphia Metropolitan area" and because "during 1993, no complaints or grievances regarding race and/or disability and staff behavior toward patients or families were filed."³⁹⁰

OCR's finding here that a lack of complaints suggests that there was no differential treatment on the basis of race and therefore no compliance violation is a faulty conceptualization of investigative purpose and technique. That no other complaints were filed should have no bearing on determining if there was differential

³⁸⁴ Freeman interview, p. 3.

³⁸⁵ Paul F. Cushing, regional manager, Region III, OCR, HHS, letter to Sharon F. Hollander, chief executive officer, Georgetown University Hospital Medical Center, Washington, DC, and others, Nov. 21, 1997 (re: docket no. 03973033) (hereafter cited as Cushing letter, Nov. 21, 1997).

³⁸⁶ *Ibid.*, p. 3.

³⁸⁷ *Ibid.*, p. 2.

³⁸⁸ Jane Rogers, Kathleen Femple, Lauren Shembry, equal opportunity specialists; Paul Cushing, regional manager, Region III, OCR, HHS, telephone interview, Feb. 24, 1999, p. 5 (hereafter cited as OCR Region III EOS interview).

³⁸⁹ Cushing letter, Nov. 21, 1997, p. 3.

³⁹⁰ Paul F. Cushing, regional manager, Region III, OCR, HHS, letter to Calvin Bland, president and chief executive officer, St. Christopher's Hospital for Children, Philadelphia, PA, undated (re: docket no.03943048), pp. 4-5 (hereafter cited as Cushing letter, undated).

treatment in this case. This is so because the lack of other complaints is a completely indeterminate fact, with ambiguous meaning. For example, it might mean that very few if any of the people in the facility's service area are aware that there are laws such as title VI that provide relief from discriminatory treatment or aware that filing a complaint will help them to access that remedy. As OCR plainly recognizes in the CRM: "[D]iscrimination against members of under-served communities may not be reflected in individually filed complaints for the precise reason that members of such communities are not aware of their rights and/or of the processes available to pursue those rights. Other discrimination victims may be too frightened to file complaints."³⁹¹

The lack of complaints might also mean people are aware of the law, but have seen how other such complaints have been investigated, and think that filing a complaint would be a waste of time. Whatever the reason for the lack of complaints filed, it can never be a basis, or even part of a basis, to make the final determination of whether there was differential treatment. This is an important matter that could be addressed in training and by ensuring that every letter of finding is reviewed by a civil rights attorney and the regional manager before it is issued.

This case illustrates a more serious problem evident in the letter of finding which states that "the complainant has not met her burden of establishing that these incidents occurred; moreover, they were related to discrimination."³⁹² It appears from the letter that the complainant was inappropriately placed in the position of having to establish a case of discrimination, when in fact it is OCR, as an enforcer of title VI, that has this responsibility. Because the complainant had no witnesses to back up her claim that her family had been discriminated against on the basis of race and because the staff involved did not admit to committing the alleged acts, OCR found no compliance problems.³⁹³ Based on such limited evidence, OCR should not claim that the complainant and her family were "not treated differently than others." At most,

OCR should claim that its *limited investigation did not reveal evidence* that the family was treated differently from others.

Incorrect Identification of Compliance Standards in Letters of Finding

It appears, based on the Commission's evaluation, that regional legal staff interact with OCR investigative and program staff on a largely ad hoc basis.³⁹⁴ As a result, there is a noticeable quality assurance problem with the agency's letters of finding themselves, which legal staff do not always review.³⁹⁵ In particular, there have been problems applying the correct standards needed to determine properly whether a given complaint was within OCR's jurisdiction or the appropriate legal standard to apply when assessing whether discrimination has occurred. A brief review of some of the agency's recent letters of finding indicates the presence of a problem in identifying for complainants and recipients the correct legal standards on which compliance findings are based.

In one example, a letter of finding from 1997, OCR addressed a complaint which charged that the recipient's failure to advertise in newspapers with predominantly minority circulation constituted a violation of title VI.³⁹⁶ OCR found that it lacked jurisdiction because HHS cannot require State or Federal agencies or private businesses to allocate any portion of their advertising to minority-owned publications. However, it appears that HHS misinterpreted the allegation and that the issue is indeed one within OCR's jurisdiction. The dollars used to pay for the advertisements originated from a federally assisted program. The Civil Rights Restoration Act of 1987³⁹⁷ expanded the purview of title VI to reach "all of the operations of . . . an entire corporation . . . which is principally engaged in the business

³⁹¹ OCR, CRM, p. 22.

³⁹² Cushing letter, undated, p. 4.

³⁹³ Ibid.

³⁹⁴ Freeman interview, pp. 7-8; Graham interview, p. 7.

³⁹⁵ Freeman interview, p. 7; Graham interview, p. 8.

³⁹⁶ Charlotte Irons, regional manager, Region V, OCR, HHS, letter to Walter L. Mathis, Sr., Grand Rapids, MI, and James K. Haveman, director, Michigan Department of Community Health, Lansing, MI, Dec. 22, 1997 (re: docket no. 05973304), p. 1 (hereafter cited as Irons letter, Dec. 22, 1997).

³⁹⁷ Pub. L. No. 100-259, 102 Stat. 28 (codified at 20 U.S.C. §§ 1681, 1687, 1688; 29 U.S.C. §§ 706, 794; 42 U.S.C. §§ 2000d-4a (1994)) (amending title VI of the Civil Rights of 1964, title IX of the Education Amendments Act of 1972, and section 504 of the Rehabilitation Act of 1973).

of providing health care[,] . . . any part of which is extended Federal financial assistance.”³⁹⁸ Contracting with print media for advertisement was part of the operations of the recipient. Therefore, the newspapers or publications were beneficiaries of a federally assisted program. Since title VI makes it illegal to discriminate against beneficiaries or “potential beneficiaries” because of race, color, or national origin, HHS was obligated to infer a prima facie case and investigate to determine if the recipients only advertised in white-owned publications. If so, HHS should then have required the recipient to show a necessary business practice, with no alternative practice that would accomplish the same objective, as to why the recipient did not advertise in minority papers.

In another case involving a complaint against a New York hospital,³⁹⁹ OCR’s analysis determined that the hospital had not engaged in a “clear and consistent pattern necessary” to establish a violation based on disparate impact.⁴⁰⁰ Two OCR regional attorneys have noted that the phrase “clear and consistent” was unfamiliar to them as a compliance standard.⁴⁰¹ One regional attorney expressed concern that this analysis was “a little fuzzy,” although in her opinion the finding itself was correct.⁴⁰² She explained that this language was inapplicable in the disparate impact context and that the analysis should have stated only that there was no evidence of disparate impact.⁴⁰³

Another regional attorney stated that this “standard” has no basis in case law.⁴⁰⁴ He described the use of this kind of arbitrary terminology, particularly in the sentence actually stating OCR’s compliance finding and the rationale for it, as “loose” and “a bit sloppy.”⁴⁰⁵ This attorney believes a better model for conducting civil rights enforcement would be for OCR to

have lawyer-investigator teams that work together more closely than is the case currently.⁴⁰⁶ In addition, he would like to see OCR strive for more consistency in its letters of finding.⁴⁰⁷

In another instance, OCR’s analysis appears to have incorrectly applied the standards for assessing the recipient’s defense and in conducting a disparate treatment analysis.⁴⁰⁸ The approaches used bore little resemblance to the well-settled standards of proof applicable in such cases. Moreover, OCR’s approach to proving discrimination appeared heavily weighted against the complainant.

According to this letter of finding, the complainant alleged that a hospital discriminated against her husband on the basis of race by moving him.⁴⁰⁹ The hospital responded to the allegation merely by stating that there was no discrimination and that six other people were “involved” in the move. OCR simply accepted this as the “legitimate” business (or medical) justification required under the applicable standard in disparate treatment cases. For OCR to have applied the appropriate standard of proof required of the recipient, at a minimum OCR should have required the hospital to have explained what the term “involved” referred to (i.e., whether it meant other patients were moved, or whether it meant others assisted in completing the move) and how and why the complainant’s husband was moved. Instead, OCR essentially shifted the burden to show evidence of discrimination back to the complainant.

Thus, OCR placed the complainant in the position of having to show that the proffered reason was a pretext without requiring any substantial evidence from the recipient for its justification. Moreover, it appears from the letter of finding that OCR neither investigated the treatment of similarly situated individuals nor conducted a serious inquiry of any kind. Rather, it appears OCR simply took the hospital at its word. What is particularly troubling is that the investigators apparently did not believe the

³⁹⁸ 42 U.S.C. § 2000d-4a(3)(A)(ii) (1994).

³⁹⁹ See Michael Carter, acting regional manager, Region II, OCR, HHS, letter to Charles S. Sims, Esq., Proskauer, Rose, Goetz & Mendelsohn, Mar. 24, 1998 (re: docket no. 02-91-3069), p. 7 (hereafter cited Carter letter, Mar. 24, 1998).

⁴⁰⁰ *Ibid.*

⁴⁰¹ Graham interview, p. 17; Miyasato interview, p. 7.

⁴⁰² Miyasato interview, p. 7.

⁴⁰³ *Ibid.*

⁴⁰⁴ Graham interview, p. 18.

⁴⁰⁵ *Ibid.*

⁴⁰⁶ *Ibid.*, p. 17.

⁴⁰⁷ *Ibid.*, p. 18.

⁴⁰⁸ See Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, letter to Debra K. Welker, nursing home administrator, IHS Care Facility, and Erma Dixon, Jan. 17, 1998 (re: docket no. 08973077) (hereafter cited as Kyle-Holmes letter, Jan. 17, 1998).

⁴⁰⁹ *Ibid.*

complainant or her allegations were credible while apparently assuming instant credibility for the recipient hospital.

Untimely Complaint Closures

Based on a review of letters of finding and other OCR documents, it appears that OCR continues to have a significant problem in completing complaint investigations in a timely manner. OCR's title VI regulations state that OCR will "make a prompt investigation" of any information, including complaints, indicating "a possible failure to comply" with title VI's nondiscrimination provision.⁴¹⁰ Nonetheless, agency documents reveal that OCR continually takes inordinate amounts of time to complete complaint investigations. OCR itself recently acknowledged the serious problems it has had with completing its investigations in a timely manner. In August 1998, the agency presented the following self-evaluation of its case management efforts: "OCR has a considerable backlog of older cases (defined as older than 180 days old). Some cases have been pending for years. In the spring, OCR finally resolved a case involving St. Luke's Roosevelt Hospital in NYC which was initiated seven years ago."⁴¹¹

OCR stated in this self-evaluation that it had undertaken several measures to address this problem. For example, OCR reported that it had initiated "case review sessions" with its regional offices, released the CRM in 1996, and completed an evaluation of new case review techniques such as prioritizing and streamlining case processing introduced in the CRM.⁴¹² According to OCR, about a quarter or more of the older cases were closed as a result of these measures.⁴¹³ However, OCR acknowledged that these were the "easiest" segment.⁴¹⁴ Moreover, OCR observed that, although its objective was to have no case older than 180 days, it would take "some time to reach this goal."⁴¹⁵

Other data detailing the untimely nature of OCR case closures are more troubling. For example, one region had five cases that took almost 3 years to complete.⁴¹⁶ OCR reported that in one instance 6 years had elapsed between the receipt date and the closure date.⁴¹⁷ Of particular concern are the several instances where OCR has taken an inordinate amount of time to complete complaint investigations involving allegations of failure to provide health care treatment or other services. For example, in one case, OCR received a complaint on July 7, 1993, but did not issue a letter of finding until nearly 4 years later on June 27, 1997.⁴¹⁸ In this case, a doctor filed a complaint alleging that the hospital where he was employed had discriminated against three of his patients on the basis of race by failing to provide outpatient services.⁴¹⁹

Among these allegations, the doctor maintained that one of his patients, a black male, was denied x-rays and another, a black female, was denied a mammogram examination.⁴²⁰ These facts help to illustrate one of the more troubling aspects of the egregious delay in completing this investigation. Unlike the civil rights enforcement agencies that address discrimination in education and employment, OCR is responsible for uncovering discrimination that may affect not just one's life opportunities but on something far more profound—individuals' health and physical well-being. In some cases, prompt investigation could be a matter of life or death. Ensuring the earliest possible resolution of complaints involving allegations of denial of access to health treatment and services must become one of OCR's top priorities. Internal policy strongly encouraging regional offices to complete such investigations and issue letters of finding within 90 days after receipt of a complaint may be one means of accomplishing this objective.

⁴¹⁰ 45 C.F.R. § 80.7(c) (1998).

⁴¹¹ David Garrison, acting director, OCR, HHS, memorandum to the Deputy Secretary, HHS, Aug. 17, 1998, p.4 (hereafter cited as Garrison memo).

⁴¹² *Ibid.*

⁴¹³ *Ibid.*

⁴¹⁴ *Ibid.*

⁴¹⁵ *Ibid.*

⁴¹⁶ OCR Region VIII, Response to Information Request, attachment 11, "Special Reports: Number of Days to Investigate Complaint from Receipt to Closure for the period, 7/1/95-1/31/96," pp. 1-2. All five complaints were closed in 1995.

⁴¹⁷ *Ibid.*

⁴¹⁸ See Ralph D. Rouse, Jr., regional manager, Region VI, OCR, HHS, letter to Judith Feuquay, administrator, Perry Memorial Hospital, Perry, OK, and Richard G. Seal, D.O., Physicians' Medical Center, Perry, OK, June 27, 1997 (re: 06933141).

⁴¹⁹ *Ibid.*, p. 1.

⁴²⁰ *Ibid.*, p. 2.

Lack of Attention to Race-based Discrimination under Title VI

The Commission's review of OCR's letters of finding and other case closure documents as well as a review of OCR's regional "monthly significant activities" reports indicates that in very few cases since at least 1997 has OCR uncovered a violation on the basis of race in the health care context in the complaint investigations and, it appears, in the compliance reviews it has undertaken.⁴²¹ Overwhelmingly, in complaints in which the allegation(s) against the recipient are based on race, OCR reports that it has "found the recipient in compliance."⁴²² In view of the racial disparities in health care documented by this report, there appears to be a gross imbalance between the extent of discrimination actually in existence, and that detected by OCR.

This imbalance manifests itself most in the area of systemic discrimination. OCR appears largely unwilling to seek out or even to recognize recipient policies and practices that adversely affect racial and ethnic minorities. Few of the Commission's interviews with regional investigative staff revealed experience with adverse impact cases. Further, regional staff could cite few current adverse impact investigations. Among the few cited is a case in Nassau County, New York, that was brought to OCR's attention by the local media.⁴²³ Moreover, when such cases have emerged, according to one commentator, OCR has been largely inept at handling them.⁴²⁴ The Commission's interviews with two private civil rights attorneys provide examples of OCR's ineptitude in the adverse impact context.⁴²⁵ Ac-

ording to these commentators, the investigations took an inordinate amount of time to come to closure, and neither found any title VI violation.⁴²⁶ In *Mussington v. St. Luke's-Roosevelt Hospital Center*,⁴²⁷ the former NAACP Legal Defense Fund (LDF) attorney who had worked on the case cited several instances that demonstrated a severe lack of understanding by OCR staff, of both the legal and investigative principles pertaining to the case.⁴²⁸ The case involved a Manhattan hospital that was proposing to move much of its neonatal intensive care unit that served the Harlem area into an area that would serve more affluent patients.⁴²⁹ During the investigation, the attorney became aware that OCR staff were unfamiliar with the basics of the civil rights laws they were responsible for enforcing. For example, at a community group meeting to discuss the case, citizens indicated that the hospital may have discriminated against medicaid patients (prohibited by the Hill-Burton Act). According to the LDF attorney, the investigator stated that such discrimination was not illegal.⁴³⁰

Investigators in the *Mussington* case also exhibited a lack of technical skills related to large-scale investigations. Although the LDF provided OCR staff with names of important witnesses well in advance of interviews, investigators reportedly asked inappropriate questions.⁴³¹ Furthermore, even after LDF staff had communicated the inadequacy of these questions, OCR allegedly failed to correct them.⁴³² One example of highly irrelevant questioning involves a statistician who had performed a disparate impact evaluation of a hospital in a case that was very similar to *Mussington*. She was interviewed as an expert, but according to this LDF attorney, OCR staff never asked her any questions relating to the substance of the report she had writ-

⁴²¹ See generally Ronald Copeland, documents sent in response to request for information including Letters of Findings and Other Closures—FY 1998; Letters of Findings and Other Closures—FY 1997; Regional Monthly Significant Activities Reports, 1998 (hereafter cited as OPO, Response to Information Request). See also "Analysis of Case Processing Database: Findings, Deficiencies, Remedies, and Sanctions," this chapter.

⁴²² See generally OPO, Response to Information Request, Letters of Findings and Other Closures—FY 1997; Regional Monthly Significant Activities Reports, 1998.

⁴²³ Morales interview, p. 3.

⁴²⁴ See Lado interview, pp. 7–8.

⁴²⁵ See, e.g., *Mussington v. St. Lukes-Roosevelt Hospital Center*, 824 F. Supp. 427 (S.D.N.Y. 1993), *aff'd*, 18 F.3d 1033 (2d Cir. 1994) (HHS OCR docket no. 02–91–3069). Lado interview, pp. 7–15. See also *In re McAllen Medical Center* (clearinghouse no. 49,113) (OCR docket no. unavailable) at 1–3 (cited in Perkins, "Race Discrimination in America's

Health Care System," p. 371). Lado interview, pp. 13–14; Perkins interview, p. 1.

⁴²⁶ Lado interview, pp. 7–15; Perkins interview, p. 1.

⁴²⁷ 824 F. Supp. 427 (S.D.N.Y. 1993), *aff'd*, 18 F.3d 1033 (2d Cir. 1994) (HHS OCR docket no. 02–91–3069).

⁴²⁸ Lado interview, pp. 7–15.

⁴²⁹ *Ibid.*, p. 8.

⁴³⁰ *Ibid.*, p. 10.

⁴³¹ *Ibid.*, p. 13.

⁴³² *Ibid.*, p. 12.

ten: "They asked her questions like where she lived . . . Ridiculous questions."⁴³³

One notable exception to this general trend of insufficient emphasis on title VI has occurred in Region I where OCR has found violations of race-based discrimination under title VI in the health care context.⁴³⁴ In cases arising in New Haven, Connecticut, OCR found that several home health care agencies were engaging in illegal discrimination in violation of the title VI regulation. Specifically, in one case, OCR investigated allegations that a home health agency's policy of providing services in New Haven based on designations of specific streets, portions of streets, or housing projects as locations where its employees would not make visits or would visit only during specified hours was creating a disparate impact on African Americans living in those areas.⁴³⁵ In the resolution agreement OCR detailed the steps necessary for the home health agency to undertake to ensure that all of its operations were in compliance with title VI.⁴³⁶ These steps included refraining "from adopting or pursuing any policy or practice designating specific streets, portions of streets or housing projects as locations where employees will not make visits or will visit only during specified hours."⁴³⁷

In the case resolution letter accompanying the agreement, OCR does not state explicitly that the home health care agency's policy constituted a violation of title VI. Rather, it states only that the agency's "adherence to the terms of the Resolution Agreement will ensure its future compliance with title VI and the HHS implementing regulations."⁴³⁸ With this statement OCR is stating implicitly that the policy likely would have violated title VI. OCR did not de-

velop actual findings and an argument to support them because the agency and OCR were able to come to a resolution agreement before such action was needed. However, it would be helpful if OCR were to keep records, perhaps a database record or a special file for such cases. Each case record could include the type of violation, an application of the essential facts to the appropriate legal standards, and the disposition of the complaint investigation at the time the resolution agreement was reached. This would increase efficiency and consistency in the handling of future cases, as well as facilitate a more comprehensive, issue-specific analysis of OCR's caseload.

Moreover, the instances of discrimination uncovered in New Haven have not yet signaled to OCR, as they should, the need to make medical redlining on the basis of race one of its program priorities. OCR should accord the same level of attention and publicity to this issue and other racially related issues that it has provided to the LEP issue. This includes the development of a policy guidance; a requirement in the AOP that each region conduct at least one compliance review per year addressing this issue; "rollouts" to health care recipients; and other forms of technical assistance, outreach, and education. For its compliance reviews OCR should target home health agencies and other health care recipients serving large urban areas in both major and minor metropolitan areas across the country.

Lack of Effective Monitoring Techniques

It appears, based on a review of OCR's letters of finding and other case closure documents, that OCR does not conduct its monitoring activities in an effective manner. For example, case resolution agreements containing agreed-upon provisions to ensure compliance do not indicate that OCR will conduct onsite visits nor do they indicate that OCR staff will prepare monitoring reports. In one case, a complainant alleged that a home health care agency complied with the wishes of white patients who requested that only non-African American staff persons be assigned to them.⁴³⁹ The complaint was resolved through the alternative dispute resolution process.

⁴³³ *Ibid.*, p. 13.

⁴³⁴ See Caroline Chang, regional manager, Region I, OCR, HHS, letter to Joanne Walsh, New Haven, CT, July 7, 1998, re: complaint no. 01-96-7801, and attached Resolution Agreement (hereafter cited as Chang letter, July 7, 1998 and Resolution Agreement re: 01-96-7801, respectively); Caroline Chang, regional manager, Region I, OCR, HHS, letter to Stephen Savitsky, Lake Success, NY, and Joyce Thomas, commissioner, State of Connecticut, Department of Social Services, Hartford, CT, May, 19, 1995 (re: complaint no. 01-94-3050), and attached Resolution Agreement.

⁴³⁵ Chang letter, July 7, 1998.

⁴³⁶ *Ibid.*

⁴³⁷ Resolution Agreement re: 01-96-7801.

⁴³⁸ Chang letter, July 7, 1998.

⁴³⁹ See Ralph D. Rouse, Jr., regional manager, Region VI, OCR, HHS, letter to Kathy Admire, branch manager, East Texas Medical Center Home Care, Mineola, TX, and Regina

The terms of the case resolution agreement required the home health agency to revise its consent to treatment form to require an agreement from the patient to accept the assignment of service providers without regard to race, color, or national origin.⁴⁴⁰ In addition, the resolution agreement required the home health agency to include revisions to its policy manual to establish procedures for withdrawal of services to patients who exhibit abusive behavior or refuse treatment from a service provider on the basis of race, color, or national origin.⁴⁴¹ The complainant also requested a formal apology, which the home health agency provided.

OCR states in the letter that "it is our determination that [the home health agency] has sufficiently addressed and resolved the issues addressed in the complaint, and we are therefore closing our file on this case."⁴⁴² OCR closed the complaint without any discussion in the letter or the terms of the resolution agreement of a timeframe for the agency to implement the changes, for OCR to review the changed policies, or for OCR to ensure that the agency was abiding by the terms of the agreement. Restricting the analysis to the case closure documents, it appears that OCR took the home health agency at its word without attempting to ensure that the agency would implement the promised changes. At a minimum, the resolution agreement should have specified the form of monitoring OCR would undertake and sanctions to be applied if the home health agency failed to comply with the agreement.

In another case, OCR received a referral from the Health Care Financing Administration indicating a Hill-Burton funded health care facility's possible noncompliance with the community service assurance (CSA) provision of the Hill-Burton regulation.⁴⁴³ According to the letter of finding, HCFA's referral provided information indicating "that patients are being transferred from the facility without appropriate screening examinations and stabilization, and that patients coming to the emergency room are not

being properly screened."⁴⁴⁴ OCR requested that the facility provide information, including the following corrective actions: a copy of the facility's "emergency transfer protocol" policy, revised to include color as a basis for nondiscrimination; and an assurance that the facility has posted the "notice of community service" signs in the emergency room, the business office, and the admissions area.⁴⁴⁵ After receiving this information, OCR concluded that the facility was "in compliance with the CSA regulation."⁴⁴⁶

Here again, OCR was confronted with a recipient that was not in compliance with the provisions of a civil rights law. OCR accepted an assurance that the recipient would change a policy without ever conducting the necessary monitoring efforts to ensure that the recipient *actually had changed its practices*. The case closure document again indicates that OCR accepts the word of recipients as a means of closing a complaint investigation, even when the recipient has implicitly acknowledged noncompliance by agreeing to take corrective action.

Similarly, a hospital policy on epidurals for LEP patients appears inadequate, even though it has been approved and OCR appears to have begun monitoring it. In particular, this policy states that "an epidural will not be administered to a laboring patient until an effective interpreter is available."⁴⁴⁷ Although this policy states that there is a procedure in place for providing interpreters, it is not clear from the policy statement that effective interpreters will *always* be available to ensure equal access to epidurals. In fact, in monitoring this policy OCR noted that although an admittance log maintained on LEP patients indicated the use of interpreters, in some cases the hospital allowed a family member to interpret and it was not clear if the hospital offered any interpreting services in those instances.⁴⁴⁸ Thus, OCR had to request additional

Staples-Lock, Mineola, TX, undated (re: 06983069), p. 1 (hereafter cited as Rouse letter, undated, re: 06983069).

⁴⁴⁰ Ibid., p. 2.

⁴⁴¹ Ibid.

⁴⁴² Ibid., p. 3.

⁴⁴³ Kyle-Holmes, Aug. 18, 1998 letter, re: #08963802.

⁴⁴⁴ Ibid., p. 2.

⁴⁴⁵ Ibid., pp. 2-3.

⁴⁴⁶ Ibid., p. 3.

⁴⁴⁷ Inho Yoon, M.D., memorandum to obstetrical resident staff, et al., Oct. 28, 1998 (re: epidurals for non-English-speaking patients in labor and delivery).

⁴⁴⁸ See Henry F. Barbour, III, acting director, Investigations Division, Region IV, OCR, HHS, letter to Sally McMillan Purnell, attorney at law, Haynsworth, Marion, McKay & Guerard, L.L.P., Greenville, SC, Feb. 8, 1999 (re: docket no. 04-98-3136).

information from the hospital. However, if OCR had simply practiced more aggressive monitoring, such as going onsite, there should have been no need to write letters back and forth between the hospital and OCR. Rather than taking swift steps to ensure this policy was appropriate in the first place, OCR's weak monitoring efforts resulted in an endless chain of paperwork that presumably did nothing to assist the patients in receiving access to quality health care.

These cases display clearly OCR's failure to ensure compliance through the use of effective monitoring activities. Although the Commission recognizes the difficulties OCR confronts in finding the resources to conduct effective monitoring on complaint investigations resolved through resolution agreements,⁴⁴⁹ certain followup activities not addressed in these cases are so crucial to the monitoring process that without them OCR cannot know with any certainty that its efforts to ensure compliance have been successful. These include onsite visits, especially those which are unannounced, as well as monitoring reports, both of which are elements of a more thorough approach to monitoring than OCR apparently has developed to date. Onsite visits in particular provide a highly effective means for OCR to know precisely the extent to which a recipient is complying with the terms of a resolution agreement.

Overall Assessment: Ineffective Complaint Investigations and Compliance Reviews

As the above discussion has illustrated, OCR's letters of finding for compliance review and complaint processing operations raise a number of serious issues as to the adequacy of OCR's efforts in uncovering and addressing violations of title VI, Hill-Burton, title IX, and non-discrimination provisions in block grant statutes. Among the most serious of the concerns raised by the descriptions of the investigations contained in the letters of finding are that the investigation is cursory without ever really looking beyond the "paper" policies of the recipients to their "real-world" practices; in a number of cases, investigations have not been completed in a timely fashion, in some cases with dire conse-

⁴⁴⁹ For example, one OCR staff person stated that there should be followup with recipients at the end of a compliance review, but OCR does not have enough staff to do so on a regular basis. OPO interview, p. 25 (statement of Mackey).

quences for the complainant (these delays are particularly egregious considering OCR's investigator workload has *decreased* in recent years); the letters themselves sometimes are incomplete and cursory; in some cases, OCR has taken an extremely long time to complete complaint investigations; OCR's monitoring and followup upon completion appear practically nonexistent; and, finally, investigations usually do not serve as the trigger for OCR staff to initiate compliance reviews. Moreover, in the rare instances when compliance reviews are undertaken as a complaint investigation followup, they generally are limited-scope reviews covering only specific issues or statutes rather than addressing a broader spectrum of issues. Finally, it appears from the Commission's review of case closure documents that the vast majority of title VI compliance reviews and complaint investigations failed to detect any significant violations.

In conducting this review, the Commission requested information on OCR's performance in conducting investigations from HHS funding recipients that had been the subject of an OCR compliance review or complaint investigation during FY 1998. OCR found very few of these recipients in noncompliance. None of the recipients found in noncompliance responded to the Commission's request for information.

Of the many recipients found in compliance during FY 1998, about 20 responded. In general, most of these recipients did not respond negatively to inquiries about how they would assess OCR's efforts to identify discriminatory policies or practices. Many found in compliance had nothing negative to say about OCR's investigative technique.⁴⁵⁰ For example, one health care facility administrator wrote that "[a]s there were no findings in the compliance review, I had no

⁴⁵⁰ See Jackson L. Smith, general counsel, Memorial Hospital, Colorado Springs, CO, letter to Mireille Zieseniss, USCCR, Feb. 3, 1999; A. McPherson, president, Medical Staff, Arlington Hospital, Arlington, VA, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 31, 1999; Victoria A.B. Willis, general counsel and vice president, Legal Services, Mediacorp Health System, Fredericksburg, VA, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 16, 1999.

questions or concerns as to how the investigators reached their conclusion.”⁴⁵¹

However, a few recipients did offer some very telling commentary about their experience with OCR. The president of a Montana hospital made several scathing remarks that offer insight into some of the more significant problems with OCR’s investigative efforts. He stated:

Looking back over the case file in question, I am sore about two matters. The first is the original COBRA investigation by HCFA and their referral to OCR. . . . A modicum of judgment on the part of the investigator would have dismissed this as not a COBRA violation The second problem with this case was the inordinate time it took for OCR to resolve this case. It was fully two years from the original HCFA notice and referral to OCR (June 17, 1996) until we received a final determination (June 29, 1998). Every single contact to us for data included a demand that a response be received in 15 days. To say that our timeliness was not reciprocated is the mildest form of understatement. It was particularly exasperating to be asked for the same information on multiple occasions.⁴⁵²

In another instance, a hospital investigated by OCR stated the following about the accuracy of OCR’s description of the facts, the clarity of OCR’s explanation for conducting the review, and the credibility of its evidence as provided in OCR’s letter of finding: “While the letter refers to possible non-compliance with federal regulations in regards to two patients, it intermingles the factual situations of the two cases. In addition, the factual description is erroneous.”⁴⁵³ These remarks reflect the very same observations about OCR’s enforcement efforts made by the Commission in its assessment: poor descriptive and analytical quality of letters of finding; questionable investigative technique and expertise; untimely completion of investigations; an

onerous burden to provide responses to information requests in 15 days, which appears to be placed on both parties in a complaint investigation; and the overall inefficiency in conducting investigations.

Comments such as these reflect the significant concerns indicated by the Commission’s more indepth assessment of OCR enforcement efforts. Overall, the cases observed in OCR’s letters of finding for FY 1995 to FY 1998 reflect the themes that resonate throughout OCR’s civil rights enforcement operations: the lack of a sound, comprehensive, clearly focused action plan to uncover race discrimination in the health care industry; the lack of written, standardized, rather than *ad hoc*, procedures and investigative plans for implementing civil rights enforcement activities; and the failure to interact with other key HHS agencies. For example, OCR relies on medical experts from HHS operating divisions to some extent in making its cases for discrimination, but it does not have guidelines or policy requiring the use of experts and the manner in which they will be provided to OCR, to ensure that they will in fact be provided whenever OCR needs their expertise to develop a case. Aside from this deficiency, the letters themselves, particularly the ones discussed above, suggest an emphasis on statistics with little or no effort to determine differences in the *quality* of care between white and minority patients. This review of OCR’s letters of finding also indicates that in the last several years, OCR has limited the focus of its compliance reviews so narrowly that it has addressed very few issues under title VI and Hill-Burton and almost none relating to title IX. Finally, this review suggests that, as many observers have noted, OCR appears to remain, for the most part, complacent and passive in its approach to enforcement.

Barriers to Uncovering Compliance Violations

There are a number of barriers to effective enforcement, several of which are seemingly beyond the control of OCR itself in that other HHS agencies must work with OCR to remove them. Each of the barriers suggests areas where OCR must undertake new and more proactive efforts to more effectively execute its responsibilities. These efforts include developing working relationships in which the other agencies provide

⁴⁵¹ Sandra Woods, R.N., B.S.N., director, Quality Improvement, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 1, 1999, p. 1.

⁴⁵² Lawrence L. White, Jr., president, St. Patrick Hospital, Missoula, MT, letter to Mireille Zieseniss, Office of Civil Rights Evaluation, USCCR, Feb. 15, 1999, p. 1.

⁴⁵³ Robert W. Ladenburger, president and chief executive officer, St. Peter’s Hospital, Helena, MT, letter to Mirielle Ziesiness, USCCR, Washington, DC, Mar. 25, 1999. This is one of many cases illustrating the Commission’s concern that OCR letters of finding indicate cursory investigations with limited application of investigative techniques crucial in making accurate determinations of compliance. See Kyle-Holmes, Aug. 18, 1998 letter, re: #08963801.

support to OCR in completing *its* mission rather than the other way around.

Availability of Medical Expertise

OCR relies on medical and scientific research expertise provided by other HHS agencies. However, the availability of these medical experts to OCR is limited by their job responsibilities to their own agency, which take priority over any assistance OCR may need. HHS currently does not seek to ensure that OCR has medical expertise available when needed. OCR has no formal mechanism such as memoranda of understanding or procedural guidelines to invoke assistance from personnel in these agencies when it is needed. As a result, OCR may not be able to avail itself of the expertise of Public Health Service doctors or NIH researchers because they are working on other projects.

With regard to this availability problem, several OCR regional staff stated that it can be difficult for OCR to obtain the medical expertise needed to challenge a recipient's medically related rationale.⁴⁵⁴ One regional attorney stated that, based on his experience, OCR's ability to obtain needed expertise from the Public Health Service (PHS), National Institutes of Health (NIH), or the Centers for Disease Control (CDC) sometimes has been extremely limited.⁴⁵⁵ This attorney stated that without the expertise of medical doctors and researchers from these agencies, OCR's ability to dispute medical opinions successfully is hindered.⁴⁵⁶

When important HHS operating divisions such as CDC or NIH are not willing to have their doctors readily available to lend their knowledge and expertise when OCR is attempting to resolve particular cases, OCR has difficulty defending its credibility as an investigative agency.⁴⁵⁷ According to a regional attorney, it appears that OCR is not a priority among the operating divisions, whose key staff, in some instances when OCR has requested their assistance, have informed OCR that they are extremely busy and have other priorities, especially when they are

preparing for conferences.⁴⁵⁸ Furthermore, OCR does not have the funds to purchase outside medical consultation to get neutral opinions in difficult cases.⁴⁵⁹ This attorney stated that he would recommend that, if assisting OCR's investigative activities cannot be made a priority among medical professionals working in the operating divisions, that, at a minimum, OCR should consistently have available, on a contractual basis, outside experts to lend their opinions as cases are being developed.⁴⁶⁰

Another attorney stated that he does not think that OCR has a good pool of experts on which to rely during investigations.⁴⁶¹ Region VII EOS stated that if a complaint were about quality of care, it would not be investigated, although complaints about denial of services are investigated.⁴⁶² These EOS staff noted that it is difficult to get medical assistance to question a doctor's medical opinion, but they have done it in the past. They do not have the funds to hire medical experts, but sometimes they can get free consulting. Once they had a regional attorney on detail from the Dallas Regional Office who was able to get medical advice from CDC.⁴⁶³

The inability to routinely get quality medical advice and expertise has had a negative effect on OCR's ability to uncover and prove violations of title VI. However, if HHS made it a priority to ensure that OCR attorneys have medical expertise available when it is needed and not only when time allows, OCR's ability to conduct thorough investigations would be greatly enhanced. It seems that an optimum situation would be for OCR to have medical experts assigned to work with OCR on a permanent basis. Just as OCR has data collection and policy experts, it also should have experts in medical/health care delivery. These experts would be staffed in a specialized office within headquarters. Similar to OMPE and OPO, OCR could form an Office of Medical Guidance. At a minimum, memoranda of understanding or other formal agreements between OCR and each of the key operating divisions is necessary. Such agreements could en-

⁴⁵⁴ OCR Region VII EOS interview, p. 5; Freeman interview, pp. 10-11; Graham interview, p. 15.

⁴⁵⁵ Freeman interview, p. 10.

⁴⁵⁶ *Ibid.*, pp. 9-10.

⁴⁵⁷ *Ibid.*, p. 10.

⁴⁵⁸ *Ibid.*, p. 11.

⁴⁵⁹ *Ibid.*

⁴⁶⁰ *Ibid.*

⁴⁶¹ Graham interview, p. 3.

⁴⁶² OCR Region VII EOS interview, p. 5.

⁴⁶³ *Ibid.*

sure that medical expertise is available to OCR whenever it is needed by establishing a rotating basis for designating medical doctors and researchers to work with OCR as needed on pending cases.

Availability of Complete Data

The Commission's evaluation of OCR's enforcement activities indicates that the agency does not always, and may not be able to, make effective use of statistical evidence in establishing cases of discrimination under title VI. A finding of a title VI violation requires proof that the recipient engaged in a policy or practice that resulted in discrimination on the basis of race, color, or national origin, whether the recipient intended to practice such discrimination or whether the practice was neutral but nonetheless caused an adverse impact. Therefore, in order to establish that the cause of a racial disparity in health care service delivery is a violation of title VI, an OCR investigation must seek to determine the practice that created the statistical disparity.

In establishing proof that a recipient has violated title VI's nondiscrimination mandate at the systemic level, both with respect to a showing of intentional and disparate impact discrimination, statistics play a crucial role. For example, for OCR to show that a recipient is engaging in intentional discrimination on the basis of race, statistical evidence may be used to lend credibility to claims of individual discrimination made by individuals in complaints against health care recipients filed with OCR. However, the Commission's evaluation of OCR's data analysis activities indicates that the agency is severely hindered in its access to and ability to manipulate to data to make compliance determinations.

One commentator familiar with title VI discrimination issues in the health care context has stated that "patterns [of discrimination] begin to appear" once you have adequate data available.⁴⁶⁴ This commentator, a civil rights attorney who is a seasoned litigator in the field of civil rights in health care, stated:

If there were better data, not just OCR, but also private researchers, and CDC, would be able to study it,

⁴⁶⁴ Bonnyman interview, p. 23.

and patterns of discrimination would emerge. Those patterns would appear, for instance, if you were using claims forms that allowed you to control for diagnosis, age, and the other factors that confuse the analysis. Once these patterns of discrimination became evident, it would be much easier to stop the practices, because the public would be behind the effort.⁴⁶⁵

In accord with these observations, several OCR regional staff have stated that there often is a lack of available data to adequately show an adverse impact on a racial minority.⁴⁶⁶ One regional attorney described a case in which OCR attempted to determine potential racial/ethnic disparities in access to an HMO by looking at: (a) raw racial/ethnic statistics in terms of persons who are eligible for medicare; (b) marketing efforts by the HMO made to the medicare group, and if those strategies included special efforts to reach minority groups and improve their access; and (c) efforts (and problems encountered) to recruit minority health care providers and other individuals who are likely to provide health care services to a minority population.⁴⁶⁷

In this case, based on the information provided by the HMO, OCR was not able to establish that a civil rights violation existed in the area of access to health care. The attorney stated, "You can't detect discrimination caused by a facility, or structure of a health care environment, until you examine the data on people who have been treated."⁴⁶⁸ However, the attorney stated OCR's access to this data was very limited. As a result, OCR was not able to obtain "all the information the agency really needed."⁴⁶⁹ He indicated that if he had been able to gain access to and analyze certain information that the HMO was not required (by regulations) to provide to HHS, then maybe he could have found a violation.⁴⁷⁰

It appears that OCR has difficulty both in showing the presence of disparities and establishing a nexus between those disparities and a specific policy or practice of a recipient. Both of these showings are necessary for OCR to find a

⁴⁶⁵ Ibid.

⁴⁶⁶ See Freeman interview, p. 7; Kyle-Holmes interview, p. 7.

⁴⁶⁷ Freeman interview, p. 5.

⁴⁶⁸ Ibid., p. 6.

⁴⁶⁹ Ibid., p. 5.

⁴⁷⁰ Ibid.

violation of title VI.⁴⁷¹ However, if OCR, through a compliance review, could discover racial disparities, its ability to establish such a nexus would be greatly enhanced. In connection with the need to show this nexus between racial disparities and particular practices of health care funding recipients, one regional attorney stated that although OCR may suspect the presence of a compliance violation, it often cannot document it because it does not have the data necessary to provide sufficient evidence of a violation.⁴⁷² Another regional attorney stated, "There is a prevalent recognition that there are disparities in health care and yet it seems difficult to tie what goes on in the managed care industry to any specific practice . . . OCR has been somewhat mystified about where to look for the cause of minority health discrepancies."⁴⁷³

This evidence is crucial in making a determination that a recipient has violated title VI. The lack of data, therefore, significantly inhibits OCR's ability to develop cause findings in both compliance reviews and complaint investigations. To uncover violations of title VI, at a minimum, OCR must have sufficient data available on each of the following:

- The manner in which services are provided by the program.
- The race, color, and national origin of the population eligible to be served.
- The location of existing or proposed facilities and information on whether the location could have the (unintended) effect of denying access to any person on the basis of race/ethnicity and/or gender.
- Racial/ethnic and gender composition of program participants.
- Treatments provided to patients (by race, ethnicity, and gender).
- Racial/ethnic and gender composition of applicant's/recipient's staff.
- Data on the use of bilingual employees to work with program participants and other

⁴⁷¹ See 45 C.F.R. § 80.3(b)(2) (1998). See also Marianne L. Engelman Lado, "Breaking the Barriers to Health Care: A Discussion of the Role of Civil Rights Litigation and the Relationship Between Burdens of Proof and the Experience of Denial," *Brooklyn Law Review*, vol. 60 (spring 1994), pp. 257-65.

⁴⁷² Freeman interview, p. 7.

⁴⁷³ Graham interview, p. 7.

beneficiaries who have limited English proficiency.

- Lawsuits filed against the applicant/recipient alleging discrimination.
- Descriptions of any applications for assistance pending at other Federal agencies.
- Descriptions of any civil rights compliance reviews conducted in the prior 2 years.
- Information on whether the applicant/recipient has been found in noncompliance with civil rights laws.

Development and Implementation of Compliance Reviews

Although the lack of clearly defined objectives and pervasive lack of thoughtful preparation and analysis that have characterized OCR's planning and implementation of compliance reviews addressing race discrimination in health care have been mentioned above, it bears repeating since it appears crucial to understanding the significant problems OCR currently faces as a civil rights enforcement agency. Without more precise objectives and more carefully planned approaches to designing and implementing compliance reviews, OCR will never be able to effectively evaluate areas, such as managed care and health insurance, where the presence of disparities along racial lines is not easily attributable to one or even several particular practices. As a result, OCR's current compliance review efforts in these areas often are merely exercises in futility that fail to establish whether well-documented racial disparities in health status and outcomes are the result of illegal discrimination under title VI.

In particular, the development of detailed, thorough, well-researched investigative plans focusing on a particular issue seems to be a problem for OCR. However, while OCR pursues its abstruse, unfocused compliance review activity, there is a wealth of research available to OCR that if used properly, could form the basis of specifically focused, far more efficient compliance reviews. For example, the discussion above on site selection refers to a study published in the *Journal of the American Medical Association* showing that black people, women, and the poor are less likely to receive kidney transplants than men, white people, and the affluent.⁴⁷⁴ This arti-

⁴⁷⁴ Alexander and Sehgal, "Barriers to Cadaveric Renal Transplantation."

cle was disseminated to regional staff as an attachment to a weekly information report from headquarters.⁴⁷⁵ It provides a very specific issue to target in developing an investigative plan for a compliance review. Identifying a disparity based on race or sex in kidney transplantation procedures within a recipient facility provides a specific, narrowly focused objective. Determining the extent to which the disparity is caused by factors that can be addressed in a negotiated agreement between OCR and the facility or through technical assistance or some other form of action also is a reasonable goal.

To be fair, uncovering subtle forms of race or sex discrimination that exist in the health care system does present significant obstacles that have been alluded to in the discussion above. Even with adequate statistical evidence, it is very difficult to establish a relationship between a particular practice and statistical evidence of health care access and outcomes. However, with specific, clearly identified objectives, OCR is much better prepared to make this connection and to determine whether it constitutes a violation of title VI or any of the other statutes OCR enforces. The problems in rooting out discrimination in the health care system are complex, however, and a stronger emphasis on developing a careful, indepth, and ongoing review of available literature as exemplified by the JAMA article on racial differences in kidney transplantation may be needed to provide new insights in developing investigative plans for compliance reviews. Aside from providing a clearly defined objective, the literature may help OCR investigative staff to better conceptualize compliance problems.

For example, a recent research study illustrates the difficulties confronting OCR in developing effective investigative plans while at the same time providing a useful model for defining objectives clearly and manipulating data to establish the all-important connection between evidence and recipient policies and practices. In an article appearing in the *New England Journal of Medicine* in February 1999, researchers published the results of a study that showed doctors are far less likely to recommend rigorous and more sophisticated cardiac tests for black people and women than for white men with

identical complaints of chest pains.⁴⁷⁶ The widely publicized article described a study in which researchers found that doctors prescribed the cardiac catheterization only 60 percent as often for black males and women and 40 percent as often for black women as compared with white men.⁴⁷⁷

This study is singularly important. According to the *Washington Post*, it is the first large-scale study to focus exclusively on treatment decisions made by doctors rather than merely documenting the already well-known disparities in health care status and outcomes.⁴⁷⁸ The authors of the study could not draw any inferences of overt racism or sex bias from their findings.⁴⁷⁹ However, they suggested instead that the problem may be the result of "subconscious perceptions rather than deliberate actions."⁴⁸⁰

If OCR could shift its focus, as this study has done, to include not only evidence of disparities but also an emphasis on eradicating bias among medical practitioners and administrators themselves, it may be better able to identify policies and practices that need to be changed, as well to develop creative solutions to address the "subconscious perceptions" that appear to be a factor in creating the disparities in health care that exist across racial and gender lines. For example, by developing investigative plans that include a strong focus on medical professionals among health care funding recipients, including doctors, nurses, and administrators, OCR may be better able to gain a more complete, balanced perspective on the subjects of its compliance reviews.

Potential Disincentives to Finding Violations

Two OCR regional attorneys indicated that they believe one possible barrier to finding violations is that there are "built-in" disincentives to find violations.⁴⁸¹ For example, one of these at-

⁴⁷⁵ Haynes letter, Oct. 23, 1998.

⁴⁷⁶ See Kevin A. Shulman and others, "The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization," *New England Journal of Medicine*, vol. 340 (Feb. 25, 1999), pp. 618-26.

⁴⁷⁷ *Ibid.*, pp. 618-19.

⁴⁷⁸ Avram Goldstein, "GU Study Finds Disparity in Heart Care," *Washington Post*, Feb. 25, 1999, pp. A-1, A-13.

⁴⁷⁹ *Ibid.*, p. A-13.

⁴⁸⁰ *Ibid.*

⁴⁸¹ Graham interview, p. 20; Roger Geer, regional attorney, Region VI, Office of General Counsel, Civil Rights Division,

torneys has suggested the possibility that part of the reason why OCR finds so few violations is that there are incentives, some more subtle than others, for investigative staff to find no violation. This attorney stated:

There is still a temptation not to [find violations] for investigators, because their job descriptions are written partly to how many cases they can do per year; it is almost like a quota and it is easier to make the quota with no violation cases. There are subtle or not so subtle incentives to keep working on your no violation cases and make sure you meet the quota and not to work on violation cases and let them drag out because they are harder, more difficult.⁴⁸²

A second regional attorney stated that he believes OCR places a great deal of emphasis on numbers.⁴⁸³ He stated that there is a quota system, established at OCR headquarters, for the number of cases to be closed.⁴⁸⁴ He also stated that, as a result, complex cases on which OCR could and should spend more time, are closed.⁴⁸⁵ This attorney recommended that OCR create a weighted point system to allow regional investigative staff more time closing complex cases.

The presence of a quota or "quota like" system would help to explain why there are so few cause findings in cases involving investigations into race discrimination under title VI since this appears to be a very difficult area in which to establish the presence of discrimination. Finding such a violation often means relying on a showing of discrimination based on disparate impact.⁴⁸⁶ This can be very difficult to prove, particularly since it requires the use of data that may not be available to OCR because of limited data collection among recipients.⁴⁸⁷ Even more difficult may be establishing a case based on disparate treatment since it requires a showing of intentional discrimination, and numerous reports indicate racial discrimination in the health care industry often is of a subtle nature, which

can make it impossible to prove intentional discrimination.⁴⁸⁸

In any case, a review of position descriptions of regional equal opportunity specialists tends to indicate that their job duties and requirements provide an incentive for closing cases as quickly as possible while completing as many as possible in a given period. For example, a Region VI position description for EOS staff states that an EOS must complete work "including investigative reports and files and letters of agreement [which] are reviewed for technical soundness, completeness, and conformity to program requirements within established target dates."⁴⁸⁹ The extent to which meeting target dates plays a role in how thoroughly individual EOS staff members conduct their investigations is unclear. However, based on the observations presented above of the two regional attorneys, together with the dearth of noncompliance findings in OCR's title VI race discrimination cases, it appears that maintaining a balance between meeting targets dates and conducting thorough investigations may require a significant amount of compromise.

Insufficient Investigative Training

The Commission's evaluation strongly indicates that OCR's ability to enforce civil rights statutes and regulations is hampered by insufficient staff training. These indicators include the assessments of OCR regional legal staff as well as commentators reviewing OCR's enforcement efforts. Several OCR staff stressed the need for training, noting that many of the investigators have not had formal investigator training.⁴⁹⁰ This has caused concern among some OCR staff. For example, one OCR regional attorney stated that she thinks guidance for investigative staff is needed in regard to addressing and resolving licensure cases in which race, ethnicity, and/or disability is alleged.⁴⁹¹

Often, attorneys provide training on investigative techniques and other issues, but it is not

HHS, telephone interview, Feb. 3, 1999, p. 6 (hereafter cited as Geer interview).

⁴⁸² Graham interview, p. 20.

⁴⁸³ Geer interview, p. 6.

⁴⁸⁴ Ibid.

⁴⁸⁵ Ibid.

⁴⁸⁶ See vol. II, chap. 3.

⁴⁸⁷ See above for a discussion on data collection and reporting requirements.

⁴⁸⁸ See chap. 3.

⁴⁸⁹ Ralph D. Rouse, regional manager, Region VI, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 15, 1999, re: request for information, attachment 1, "Position Description for Equal Opportunity Specialist, GS-360-9," p. 2 (hereafter cited as OCR Region VI, Response to Information Request).

⁴⁹⁰ OCR Region VII EOS interview, p. 5. See chap. 3.

⁴⁹¹ Golightly-Howell interview, p. 3.

done in a consistent manner.⁴⁹² Most employees think there is a need for more training, particularly in title VI health care issues, case law, managed care issues, investigative techniques, the difference between disparate impact and disparate treatment, regulations, case law, and the application of case law to the regulations.⁴⁹³ OCR staff also stated that refresher training was needed to address new ideas and new ways of handling cases.⁴⁹⁴

For example, the attorney in Region III stated that improvement is needed in investigative techniques. He noted that the equal opportunity specialists could benefit from procedural training in this area, such as how to ask the right questions.⁴⁹⁵ Similarly, an attorney who has been active in civil rights and health care issues noted several instances where OCR had “bungled” cases and asked standard questions that were not appropriate to the specifics of the case.⁴⁹⁶ This attorney stated that in a case concerning hospital relocation, OCR staff failed to ask an architect about his plans for a hospital; instead, OCR asked the architect about the area surrounding the hospital and if he had ever used the hospital.⁴⁹⁷ These were clearly inappropriate questions for this witness and did not provide the information necessary for OCR to investigate the case properly. In fact, this attorney noted that, overall, OCR did “a rotten investigation” in this case.⁴⁹⁸ The complainants agreed to mediation, which broke down, and eventually the case was dismissed from court on statute of limitations grounds. Meanwhile, OCR had closed the

⁴⁹² Geer interview, p. 2; OCR Region I EOS interview, p. 6; Freeman interview, p. 2; Rhinehart interview, p. 2; Halverson interview, p. 7; Miyasato interview, p. 2.

⁴⁹³ Rouse interview, p. 1; OCR Region VI EOS interview, p. 4; Kyle-Holmes interview, p. 6; Rhinehart interview, pp. 2, 4; OCR Region VII EOS interview, p. 5.

⁴⁹⁴ OCR Region I EOS interview, p. 7.

⁴⁹⁵ Rhinehart interview, p. 4.

⁴⁹⁶ Lado interview, pp. 9–12.

⁴⁹⁷ *Ibid.*, pp. 9–10 (discussing OCR’s part in the *Mussington v. St. Lukes-Roosevelt Hospital Center* case, docket no. 02–91–3069). *See also* Carter letter, Mar. 24, 1998, p. 7). For the district court’s opinion granting dismissal for lack of timeliness in the corresponding private action, *see* *Mussington v. St. Luke’s-Roosevelt Hospital Center*, 824 F. Supp. 427 (S.D.N.Y. 1993), *aff’d*, 18 F.3d 1033 (2d Cir. 1994) (*per curiam*).

⁴⁹⁸ Lado interview, p. 14.

case, finding no violation.⁴⁹⁹ The attorney stated, “We could have just withdrawn the case, but instead we now had a finding of ‘no violation’ which, although it didn’t have any precedential value, let recipients know that these cases are very hard for complainants to win.”⁵⁰⁰

The attorney provided another example in which OCR staff “totally didn’t understand what the claims were, and [were unable to] match witnesses with the claims” and, as a result, “simply didn’t understand that discrimination against Medicaid recipients is illegal.”⁵⁰¹ Further, this attorney alleges that the HHS Office of General Counsel was unable to tell her if OCR was using the standard of intent or impact for this claim.⁵⁰²

An attorney with the National Health Law Program also expressed doubt about OCR’s ability to properly investigate and handle important civil rights issues. This attorney agreed that it is important to develop cases that can use title VI to create positive change.⁵⁰³ However, she noted that her instincts “would not be to go to OCR with that because I don’t have confidence that that would be an issue they could handle.”⁵⁰⁴

Analysis of OCR’s Database: Final Dispositions of Cases

OCR counts the number of violations and corrective actions based on the number of letters issued during any given fiscal year. Violations and corrective actions are issued in compliance activities such as complaints, compliance reviews, investigations, and pregrant award reviews. In the past, most cases were resolved through corrective action commitments on the part of recipients, rather than through administrative or legal proceedings.⁵⁰⁵ OCR continues to resolve its cases this way, and the number of cases in which OCR has cited violations has continuously declined over the past 3 years (figure 4.10).

⁴⁹⁹ *Ibid.*, p. 15.

⁵⁰⁰ *Ibid.*

⁵⁰¹ *Ibid.*, pp. 10–11.

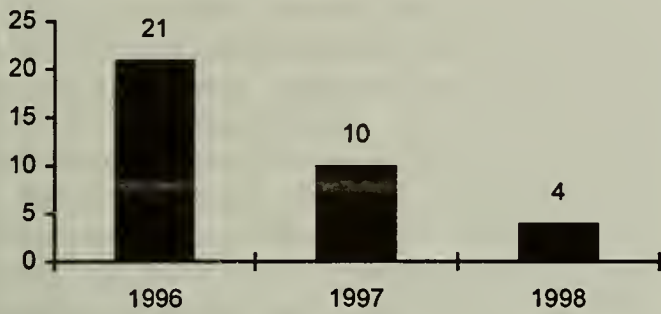
⁵⁰² *Ibid.*, p. 11.

⁵⁰³ Perkins interview, p. 4.

⁵⁰⁴ *Ibid.*

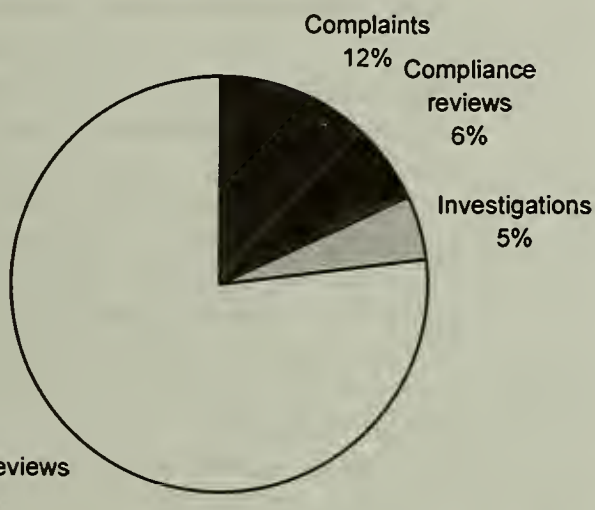
⁵⁰⁵ USCCR, *Funding Federal Civil Rights Enforcement*, p. 230.

Figure 4.10
Total Violations Cited, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

Figure 4.11
Percentage of Corrective Actions Secured by Compliance Activities, FY 1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

In FY 1996, OCR issued 21 findings of violations and 1,093 corrective actions were secured.⁵⁰⁶ Of these violations, 20 were in the area of complaints and 1 was found as a result of a pregrant review. When a violation is cited under the pregrant review activity, funds are not immediately awardable to the recipient because additional data may be needed but very seldom

⁵⁰⁶ OCR, CATS Database, FY 1996–1998. The number of violations/corrective actions issued incorporates all letters issued during the fiscal year, regardless of whether the case was closed. OCR, CATS Database, FY 1996–1998.

are funds terminated or not awarded.⁵⁰⁷ Of the 1,093 corrective actions secured, 13 percent were in complaints, 83 percent were in pregrant reviews, and less than 4 percent of secured corrective actions were in compliance reviews and investigations.⁵⁰⁸

By the end of FY 1998, OCR had cited only four violations and secured 1,147 corrective actions.⁵⁰⁹ All four cited violations were in the complaints area. Seventy-seven percent of the secured corrective actions were in pregrant reviews (figure 4.11). The percentage of secured corrective actions in the pregrant review activity has continuously declined since FY 1996, indicating that perhaps more potential medicare providers are already aware, ahead of time, of what is necessary to be in compliance with civil rights laws.

Once a violation has been cited or corrective actions secured, monitoring is critical because it is a means of following the progress of a recipient's implementation of a voluntary corrective action plan or changes mutually agreed to by the recipient. Monitoring is also a means in which to confirm that the implemented remedial action successfully corrects the identified violations. The total monitoring workload of OCR continuously declined between FY 1996 and FY 1998. In FY 1996, there were 931 cases in which monitoring was being conducted, and by the end of FY 1998 there were only 573 cases where monitoring was required (figure 4.12).⁵¹⁰ This decrease is consistent with the decrease in the percentage of corrective actions secured in the pregrant review activity.

Between FY 1996 and FY 1998, OCR had a 10 percent decrease in the number of full-time employees and its budget decreased by 0.26 percent.⁵¹¹ Although these figures appear small, if OCR already is stretching its resources and the workload of the current staff already is being consumed by complaints and pregrant award reviews, not very much is left for monitoring. Further, monitoring appears to be inconsistent across the regions. During FY 1998, in some regions monitoring consumed as much as 21 per-

⁵⁰⁷ OMPE interview, p. 8.

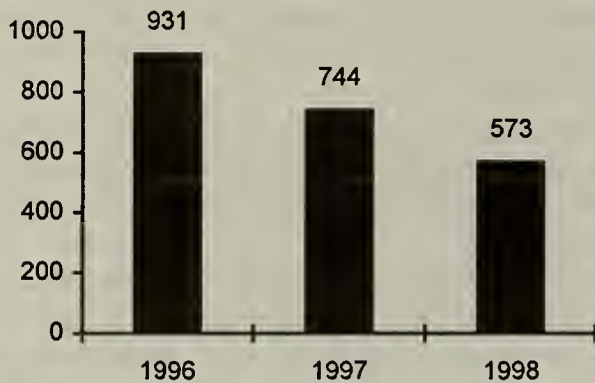
⁵⁰⁸ OCR, CATS Database, FY 1996–1998.

⁵⁰⁹ Ibid.

⁵¹⁰ Ibid.

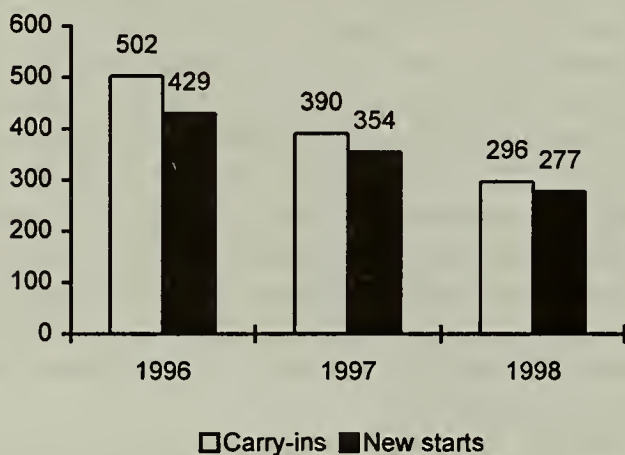
⁵¹¹ OCR, "Budget and FTE Usage History."

Figure 4.12
Total Monitoring Workload, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

Figure 4.13
Monitoring Cases Carried-in from Previous Year and Cases Received in the Current Year, FY 1996–1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1996–1998.

cent of the region's total workload, and in one region monitoring accounted for only 1 percent of the region's total workload.⁵¹²

Depending on the nature of the case, monitoring can take a year or more, and this is evident in the number of monitoring cases that are carried into one fiscal year from a previous fiscal year. During FY 1996 to FY 1998, the number of monitoring cases being carried into the fiscal

year was greater than the number of monitoring cases initiated in the fiscal year, and both the number of monitoring cases that were carry-ins and those that were new starts continuously declined during this period. In FY 1996, 502 monitoring cases were carry-ins from FY 1995, and there were 429 new cases targeted for monitoring (figure 4.13). Based on the number of monitoring cases that were still open at the end of FY 1998, OCR will carry more than 250 monitoring actions into FY 1999.⁵¹³

Partly because of the lack of resources, much monitoring is done at the desk of the regional employees. To effectively monitor recipients, OCR needs additional staff and funding to be able to go on-site, if necessary, to see what a recipient is doing or has done. Effective monitoring should also be done on a periodic basis and not just when violations or corrective actions are secured.

Administrative Proceedings and Litigation Procedures

The CRM discussion on securing compliance covers the following enforcement-related actions: moving to enforcement upon failure to achieve voluntary compliance, moving to enforcement for denial of access, and moving to enforcement for failure to implement agreement or promised corrective actions.⁵¹⁴ These discussions are very brief and provide only the barest sketch of administrative and legal proceedings for uncorrected civil rights violations.

The CRM notes that if OCR is unable to achieve voluntary compliance from a recipient engaging in civil rights violations, the agency will recommend enforcement action including: "administrative proceedings to suspend, terminate or refuse to grant or continue HHS financial assistance to the recipient"; or "referral of the case to DOJ for judicial proceedings to enforce any rights of the United States under any law of the United States."⁵¹⁵ The process of recommending either of these enforcement actions begins with a recommendation from the regional office negotiation team whenever voluntary compliance is not successful.⁵¹⁶ This recommen-

⁵¹³ OCR, CATS Database, FY 1996–1998.

⁵¹⁴ OCR, CRM, pp. 20–21.

⁵¹⁵ *Ibid.*, p. 20.

⁵¹⁶ *Ibid.*

⁵¹² OCR, Regions I–X, FY 1998 AOP, table D.

dation must include a package containing the following:

- A case summary that includes a chronology of the case, including attempts to achieve voluntary compliance, and information on Federal financial assistance.
- A litigation memorandum that should include the nature of the violation on each issue enforcement is recommended; a discussion of the applicable statutes, regulations, policy interpretation and case law; an evaluation of the evidence available to prove the case, a discussion of any possible defenses, and a draft Notice of Opportunity for Hearing, if the region recommends administrative proceedings, or a draft judicial complaint, if it recommends referral to DOJ for judicial enforcement.
- A copy of the LOF and, where available, a copy of the investigative report.
- Explanation of relevant materials received after the LOF was issued and identification of those points on which OCR and the recipient could not reach agreement.⁵¹⁷

This recommendation should then be forwarded simultaneously to the associate deputy director, Office of Program Operations and the Office of General Counsel at HHS headquarters.⁵¹⁸

OCR follows slightly different procedures in a case where a compliance violation results from a recipient's denial of access to information or failure to implement an agreement or promised corrective action. In the case of a recipient's denial of access to information, the CRM recommends that staff follow the procedures set forth for enforcement action, which may include administrative proceedings or referral to DOJ for litigation. OCR should send a final letter notifying the recipient of its authority to obtain access to the information and its intention to move to enforcement if access is not provided.⁵¹⁹ This letter should replace the violation LOF.⁵²⁰

In the case where OCR moves to enforcement action based on a recipient's failure to implement an agreement or corrective action, the CRM in-

dicates that staff should follow the procedures for normal enforcement action. However, the CRM recommends that before beginning enforcement action, the region should consider, with attorney input, the following:

- Whether the evidence is sufficient to prove a violation of the recipient's prior commitment, the underlying statutory or regulatory violation, or both.
- Whether the recipient's prior commitment, given its nature and terms, would be judicially enforceable.
- Whether OCR has fulfilled any preenforcement obligation it has under a corrective action agreement, resolution agreement, or other settlement to give the recipient written notice of, and an opportunity to respond to, apparent violations of the agreement.
- If an LOF was previously issued, whether updated findings are needed.
- If an LOF was not previously issued, whether an LOF should now be issued (e.g., to give the recipient proper notice of, and the opportunity to correct, a statutory or regulatory violation, or, in block grant situations where the Governor must be notified of a statutory or regulatory violation and given an opportunity to obtain compliance.⁵²¹

This final guidance refers to cases where OCR's postinvestigation monitoring uncovers a continuing civil rights violation that the recipient earlier had agreed to address. However, as mentioned above, OCR's guidance on the CRM and indications as to OCR's current ability to conduct appropriate monitoring, raise serious concerns. If, as the Commission has observed, OCR's efforts to conduct thorough, carefully planned monitoring activities, including onsite reviews of recipients remain limited, then OCR must develop more of a focus on this activity, both in the CRM and in any future procedural guidance or training documents.

Although OCR has procedures in place, in regards to title VI, OCR rarely reaches the stage of fund termination, let alone referral of a case to DOJ for litigation.⁵²² HHS did not refer any title VI cases to the U.S. Department of Justice in

⁵¹⁷ Ibid.

⁵¹⁸ Ibid.

⁵¹⁹ Ibid., p. 21.

⁵²⁰ Ibid.

⁵²¹ Ibid.

⁵²² See OGC interview, transcript, p. 7.

any of the years for which the Commission requested information.⁵²³

Establishing Case Precedent to Ensure Compliance

OCR, as a key Federal civil rights enforcement agency, has an important role to play in working with private civil rights advocacy groups to further the objectives of title VI non-discrimination. During the 1990s, OCR has worked with litigators from private civil rights advocacy groups on cases involving allegations of discrimination under title VI and Hill-Burton.⁵²⁴ However, OCR needs to work with civil rights advocacy groups to find cases with the potential of establishing legal precedent that can reinvigorate title VI as a vehicle for combating discrimination in the health care industry.

The prevalence of racial disparities in the Nation's health care system, and the failure of government initiatives and advocacy groups to reduce these disparities, indicate the need for a strategy to more vigorously enforce civil rights laws such as title VI to address these disparities. Working with private civil rights enforcement groups is a potentially highly effective means for OCR to ensure more vigorous enforcement of OCR in the courts. OCR needs to work with civil rights advocacy groups to develop an action plan with a specific agenda. This plan would include holding informal meetings, perhaps by conference call, to discuss cases that may have the potential to set positive precedent.

In terms of setting new precedent, OCR could more vigorously enforce title VI by seeking cases with the potential to strengthen requirements for title VI compliance. Along these lines, one regional attorney described a case in which the complainant was requesting that the health care recipient provide a language interpreter who also possessed medical training or experience interpreting in the medical field.⁵²⁵ OCR was able to persuade the recipient to upgrade the quality of its interpreter services to provide this service in its facility. However, OCR was able to achieve this result only because the recipient agreed to OCR's request as a means of ending the case.

Although relying on negotiation tactics such as the ones applied in this case have proven effective in some instances, OCR's position would be far stronger with support from case precedent, either administrative or judicial. Several OCR regional and private litigators who have worked on title VI cases in the health care context have agreed that developing means of setting positive case precedent in part by working with private advocacy groups to find cases with the potential to set strong precedent is a goal toward which OCR should be working.⁵²⁶ For example, one civil rights attorney specializing in health care issues stated, "I would start with Medicaid discrimination . . . because it is the most overt. The racial disparities in Medicaid enrollment are quite stark. . . The Medicaid population is so overwhelmingly minority that it would not be difficult for a court to see a discriminatory impact in provider's policy of not accepting Medicaid patients."⁵²⁷

Despite stating that it sought to impose stronger remedies, there are indicators that OCR is not moving in that direction. For example, the regional attorney who worked on the complaint involving a request for a medically trained language interpreter stated that he sought to have his regional office "adopt a principle" that in order for health care providers to provide effective interpreter services, the person doing the translation had to have medical training.⁵²⁸ However, OCR chose not to do this. Had it done so, it would have been moving in the direction of strengthening its compliance standards by requiring that recipients must provide medically trained language interpreters. It might be difficult to persuade a court to uphold this requirement, this attorney noted, given that OCR has not issued title VI regulations to make explicit the connection between title VI's national origin classification and limited English proficiency in the health care context.⁵²⁹ Perhaps

⁵²³ See OCR, CATS Database, FY 1996-1998.

⁵²⁴ Perkins interview, p. 2; Lado interview, pp. 7-8.

⁵²⁵ Freeman interview, pp. 8-9.

⁵²⁶ Perkins interview, p. 6; Bonnyman interview, p. 13; Golithly-Howell interview, p. 3.

⁵²⁷ Bonnyman interview, p. 13.

⁵²⁸ Freeman interview, pp. 8-9.

⁵²⁹ In the most recent Supreme Court ruling on the issue, *Lau v. Nichols*, 414 U.S. 563 (1974), the Court supported HEW guidelines requiring that "[w]here inability to speak and understand the English language excludes national origin-minority group children from effective participation in the educational program offered by a school district, the district must take affirmative steps to rectify the language

in this context, testing the viability of a stronger compliance standard in the courts might be unwise for OCR to undertake at this time. However, this does not mean that such a strategy can never be successful in this context or that it cannot be successful in other contexts.

OCR is taking some steps toward developing strategies to set stronger precedent in administrative proceedings or in the courts. For example, one OCR regional attorney has indicated that she is working with DOJ to find cases "that can go the full route, whether the administrative or judicial process."⁵³⁰ However, the attorney was referring only to cases involving racial disparities in awards of professional licenses by State agencies. OCR must take a more broad-based proactive approach in its efforts to set precedents that strengthen title VI as a civil rights enforcement mechanism. In particular, OCR should target not just issues where there have been complaints but contemporary issues publicized in news and scholarly articles, where there continues to be a wealth of new information about racial disparities. These disparities may result from violations of Federal civil rights statutes, and OCR is the only HHS agency that can undertake civil rights compliance reviews to determine the presence of illegal discrimination.

Oversight and Monitoring of HHS State-administered Block Grant Programs

In addition to enforcing civil rights statutes for the direct recipients of Federal assistance, Federal agencies are responsible for civil rights compliance in programs whose funds are funneled through the States through formula-based, State-administered block grants (or continuing State programs).⁵³¹ OCR is responsible for monitoring HHS State-administered block grant programs to ensure that civil rights provisions are incorporated into such programs. However, there are significant deficiencies in OCR's oversight and monitoring of block grant programs. Chief among these is a lack of consistent communica-

deficiency in order to open its instructional program to these students." 35 Fed. Reg. 11,595 (1970). These requirements were set forth in the context of public school recipients of Federal funding. Therefore, title VI may require language interpreter services among health care facility recipients of Federal money as well.

⁵³⁰ Golightly-Howell interview, p. 3.

⁵³¹ See *The New Wave of Federalism*, pp. 3-5.

tion between OCR and States; coordinated guidance to States on development on methods of administration; and limited efforts to assess and enforce States and their recipients' compliance with title VI, especially in health care programs.

HHS Authority for Block Grants

OCR derives its authority for monitoring State block grant programs from the Omnibus Budget Reconciliation Act (OBRA) of 1981,⁵³² with which Congress merged several Federal financial assistance programs into State-administered block grants.⁵³³ Previously, the grant programs operated by these agencies allowed recipients of funds to expend them only for narrowly defined purposes. With block grants, States have more freedom to tailor programs to meet their specific needs.⁵³⁴

With a general grant from the Federal Government, a State is authorized to distribute funds within the State to a variety of subrecipients for certain services.⁵³⁵ The increased use of block grants has led to significant changes. Competition among States for Federal monies has decreased, if not disappeared. States no longer have matching requirements for most block grants, and they have broad discretion in

⁵³² Pub. L. No. 97-35, 95 Stat. 357 (codified as amended in scattered sections of 5, 7, 8, 10, 12, 15, 19, 20, 22, 23, 24, 25, 26, 29, 31, 33, 35, 36, 38, 42, 45, 46, 47, 49, 50 U.S.C (1994 & Supp. II 1996)).

⁵³³ Pub. L. No. 97-35, § 901, § 2192(a), §§ 2601-2611, §§ 671-683, § 2352(a), 95 Stat. 357, 535, 543, 552, 818, 893, 511, 867 (1981) (codified as amended at 42 U.S.C. §§ 300w-300w-10; 300x-300x-63; 701-710; 8621-8629; 9901-9926; 1397-1397f (1994 & Supp. II 1996)). The social services block grant, codified at 42 U.S.C. §§ 1397-1397f, does not contain a nondiscrimination provision. The primary care block grant, Pub. L. No. 97-35, sec. 901, §§ 1921-1932, 95 Stat. 357, 552 (codified at §§ 42 U.S.C. §§ 300y-300y10), was repealed in 1988. See *The New Wave of Federalism*, pp. 3-5.

⁵³⁴ See Library of Congress, Congressional Research Service, Government Division, *Federalism in the United States: Toward the Third Century an Overview of Trends and Issues*, rept. no. 89-262 GOV (Apr. 17, 1989), p. 6. See also *The New Wave of Federalism*, p. 3.

⁵³⁵ U.S. Department of Justice, Civil Rights Division, "Civil Rights Responsibilities Under Block Grants," *Civil Rights Forum*, vol. 6, no.1 (fall 1992), p. 5. Subrecipients, or subgrantees, of a block grant program are recipients of federally assisted programs who receive financial assistance through an intermediate entity, such as a State agency, rather than directly from the Federal Government. Subrecipients and subgrantees typically are political subdivisions of the State agency, public or private agencies, organizations, or institutions. USCCR, *Federal Title VI Enforcement*, p. 178.

the use of the funds. However, greater State discretion limits the Federal agencies' ability to conduct preaward reviews of applicants, an important method for overseeing compliance with title VI, because the Federal Government does not control the distribution of Federal funds. As a result, greater obstacles exist to Federal civil rights enforcement in block grant programs. Although the States are in the best position to monitor the distribution of block grant funding, few consistent mechanisms exist to ensure that States sufficiently oversee compliance.

The Commission argued in its 1996 report that although State recipients are in an optimal position to monitor the distribution of block grant funds to their subrecipients, they may lack consistent and effective mechanisms to ensure their own title VI and title IX compliance responsibilities and that of their subrecipients. Consequently, the Commission stressed that Federal funding agencies, rather than State recipients, remain ultimately accountable for ensuring nondiscrimination in State-administered programs. Block grant funding requires Federal agencies to assume the same responsibility for overseeing the State agencies that DOJ is required to assume for overseeing and monitoring Federal agencies.⁵³⁶

HHS Block Grant Programs

The OBRA authorized HHS to sponsor seven block grant programs:⁵³⁷

- *Low-Income Home Energy Assistance Program*: administered by the Administration for Children and Family (ACF) to help low-income households meet home energy costs and needs.⁵³⁸
- *Community Services Block Grant Program*: administered by ACF to provide services having an impact on poverty; to provide emergency supplies, food, and related serv-

ices to counteract malnutrition among the poor; to coordinate social services programs for effective delivery to low-income individuals; and to encourage the use of the private sector to ameliorate poverty.⁵³⁹

- *Social Services Block Grant Program*: administered by ACF for social services to reduce, prevent, or eliminate dependency; achieve self-sufficiency; prevent neglect, abuse, or exploitation of children and adults; prevent inappropriate institutional care; and secure institutional care when other forms of care are not appropriate.⁵⁴⁰
- *Preventive Health and Preventive Health Services Block Grant Program*: administered by the Centers for Disease Control for activities geared to achieving the Secretary's goals for the health status of the Nation, rodent control and community fluoridation activities, emergency medical services, services for sex offense victims, and monitoring and evaluation activities.⁵⁴¹
- *Substance Abuse Prevention and Treatment Block Grant Program*: administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) to educate and counsel individuals on risks of substance abuse, provide activities to reduce the risk of alcohol and drug abuse, and ensure that individuals who request treatment are admitted to a treatment program.⁵⁴²
- *Mental Health Services Block Grant Program*: administered by SAMHSA for programs such as community mental health centers, child mental health programs, rehabilitation programs, peer-support programs, mental health primary consumer-directed programs.⁵⁴³
- *Maternal and Child Health Services Block Grant Program*: administered by the Health Resources and Services Administration

⁵³⁶ USCCR, *Federal Title VI Enforcement*, pp. 3, 78, 178.

⁵³⁷ See 42 U.S.C. §§ 300w-300w-10; 300x-300x-63; 701-710; 8621-8629; 9901-9926; 1397-1397f (1994 & Supp. II 1996). The primary care block grant, Pub. L. No. 97-35, sec. 901, §§ 1921-1932, 95 Stat. 357, 552 (codified at §§ 42 U.S.C. §§ 300y-300y10), was repealed in 1988. See *The New Wave of Federalism*, pp. 3-5.

⁵³⁸ HHS, Administration for Children and Families, "Low Income Home Energy Assistance Program (LIHEAP)," accessed at <<http://www.acf.dhhs.gov/programs/liheap>> on Jan. 16, 1999; 42 U.S.C. § 8624(b)(1)(A)-(D) (1994 & Supp. II 1996).

⁵³⁹ 42 U.S.C. §§ 9901-12 (1994 & Supp. II 1996); Executive Office of the President, Office of Management and Budget, *1998 Catalog of Federal Domestic Assistance*, 1998, p. 1164 (hereafter cited as OMB, 1998 CFDA).

⁵⁴⁰ 42 U.S.C. §1397-1397(f) (1994 & Supp. II 1996); OMB, 1998 CFDA, p. 1197.

⁵⁴¹ 42 U.S.C. § 300w-300w-10 (1994 & Supp. II 1996); and OMB, 1998 CFDA, p. 1342.

⁵⁴² 42 U.S.C. § 300x-21-300x-35, 300x-51-300x-64 (1994 & Supp. II 1996).

⁵⁴³ 42 U.S.C. § 300x-300x-9, 300x-51-300x-64 (1994 & Supp. II 1996).

(HRSA), Bureau of Maternal and Child Health, for access to quality maternal and child health services to mothers and children, particularly those with low income or with limited availability of health services.⁵⁴⁴

Enforcement of Nondiscrimination Provisions in Block Grant Programs

Under OCR's explicit block grant procedures, States that participate in HHS block grant programs must not violate title VI's nondiscrimination provisions.⁵⁴⁵ In this respect, OCR's block grant procedures are similar to requirements for other federally funded programs that flow through States.⁵⁴⁶ However, the 1981 OBRA also requires that HHS refer findings of civil rights violations in block grant programs to the Governors of the noncompliant States so that corrective action can be taken to restore compliance and eliminate discrimination.⁵⁴⁷ For each block grant program, with the exception of the social services block grant program, the Governor's responsibility to secure a State agency's voluntary compliance is explicitly required under the

nondiscrimination provisions of each HHS block grant program.⁵⁴⁸

The director of Policy and Special Projects Staff (PSPS) acknowledged that the block grant procedures are novel; in other programs a State is not usually informed about a program that has violated a civil rights statute, nor would it be responsible for ensuring voluntary compliance.⁵⁴⁹ However, the director of PSPS noted that OCR's title VI enforcement role in block grant programs is basically the same as in other programs.⁵⁵⁰ She also recognized that States' responsibilities, such as to correct for noncompliance and develop and submit an appropriate corrective action plan, do not reflect a change in States' title VI obligations in the context of block grant programs; OCR does not delegate any civil rights compliance, implementation, monitoring/oversight, and enforcement responsibilities to State agencies that receive block grant funds.⁵⁵¹ According to OCR, State agencies do not conduct preaward desk audits, compliance reviews, or complaints investigations.⁵⁵²

Regional offices are provided little guidance from headquarters on the issue of State monitoring and formal agreements with the States. For example, the regional manager for Region VII stated that he knows no specifics about block grant programs unless he receives a complaint regarding a block grant program. He stated that

⁵⁴⁴ 42 U.S.C. § 701(a)(1)–(a)(4) (1994 & Supp. II 1996); Gary Carpenter, public health analyst, HHS, Health Resources and Services Administration, Sept. 18, 1998, telephone interview (hereafter cited as Carpenter interview).

⁵⁴⁵ OPO interview, pp. 33, 34, 42, 43 (statement of Mackey).

⁵⁴⁶ U.S. General Accounting Office, *Federal Agencies' Block Grant Civil Rights Enforcement Efforts Status Report*, GAO/HRD-84-82 (Sept. 28, 1984), p. 29 (hereafter cited as GAO, *Block Grants*).

⁵⁴⁷ 42 U.S.C. §§ 300x-7(b); 300w-7(b); 708 (b); 8625(b); 9906(b) (1994 & Supp. II 1996); 51 Fed. Reg. 2,806 (1986). See Betty Lou Dotson, director, OCR, HHS, Letter to Governor of each State, no date (re: notification of Governors' responsibilities pursuant to the nondiscrimination provisions of Health and Human Services block grant programs) (hereafter cited as OCR, Letter to Governors); OCR, CRM, p. 52; HHS, "Block Grant Fact Sheet," p. 2; Haynes interview, p. 3; GAO, *Block Grants*, p. 55. The deputy to OCR's associate deputy director views OCR's provision to refer compliance violations to Governors as an additional requirement to address the peculiarities of block grant programs, rather than as a change in OCR's title VI enforcement role; States that participate in HHS block grant programs must not discriminate, similar to requirements for other federally funded programs. See OPO interview, pp. 33, 34, 42, 43 (statement of Mackey). Thus, HHS does not impose distinct title VI obligations on States that participate in block grant programs versus categorical or other programs. See OPO interview, p. 43 (statement of Mackey). See also GAO, *Block Grants*, pp. 13–14; O'Brien and Mackey interview, pp. 7–8 (statement of O'Brien); PSPS interview, p. 20 (statement of Haynes); and Haynes interview, p. 5.

⁵⁴⁸ See, e.g., 42 U.S.C. § 9906(b) (1994 & Supp. II 1996). With respect to HHS' Community Services Block Grant Program, as an example, "Whenever the Secretary determines that a State that has received payment under this chapter [Subtitle B—Community Services Block Grant Program] has failed to comply with subsection (a) of this section [prohibition of discrimination on the ground of race, color, national origin, or sex, as well as age under the Age Discrimination Act of 1975 and handicap as provided in section 504] or an applicable regulation, he shall notify the chief executive officer of the State and shall request him to secure compliance . . . within a reasonable period of time, not to exceed 60 days." *Id.*

See also HHS, Office of the Secretary, "Fact Sheet: Nondiscrimination in Block Grant Programs," p. 2 (hereafter cited as HHS, "Block Grant Fact Sheet"); OCR, Letter to Governors; PSPS interview, pp. 18–19 (statement of Haynes); GAO, *Block Grants*, p. 27.

⁵⁴⁹ Haynes interview, p. 5.

⁵⁵⁰ *Ibid.*; PSPS interview, p. 20 (statement of Haynes). See also O'Brien and Mackey interview, pp. 7–8 (statement of O'Brien); and OPO interview, p. 42 (statement of Mackey).

⁵⁵¹ Haynes interview, pp. 3–5.

⁵⁵² *Ibid.*, p. 4.

his office reviews States' methods of administration, but not regularly, and there are few resources to do so.⁵⁵³

Obligations of States

State agencies must not only determine, oversee, and track the distribution of block grant funding to their subgrantees, but they must also monitor and assess their subrecipients' compliance activities.⁵⁵⁴ Federal block grant provisions also require States to audit their own programs.⁵⁵⁵ However, because block grants are based on statutory formulas, Federal agencies have little control over the amount of funds awarded to each State.⁵⁵⁶ Similarly, States' discretion in determining the ultimate recipients of the block grant funds, as well as the amount of money each subgrantee receives, can further hinder HHS' efforts to control the allocation and use of its total program funds. Consequently, HHS can confront various obstacles when attempting to enforce civil rights statutes and regulations in block grant programs.⁵⁵⁷

Coordination Between HHS and State Recipients

Referral of Discrimination Complaints

HHS has established basic procedures for referring findings of noncompliance to Governors, based on its interpretation of States' compliance responsibilities pursuant to the nondiscrimination provisions of the OBRA and has worked with individual States to establish agree-

ments.⁵⁵⁸ The procedures were modified slightly and included in the 1996 *Case Resolution Manual*.⁵⁵⁹ Under the procedures, OCR is required to send the Governor a letter of notification and a copy of the letter of findings if a block grant recipient is found in noncompliance. The State is given not more than 60 days to secure a corrective action. In addition to offering technical assistance in devising a corrective action plan, the OCR regional office may participate in negotiations or negotiate directly with the recipient, at the Governor's discretion.⁵⁶⁰

If the Governor submits a proposed remedy that satisfies OCR's standards, the OCR regional office will incorporate it into a written agreement that is signed by the funding recipient. If the Governor's proposed remedy does not meet OCR standards, the regional office must notify the Governor in writing of its assessment and offer additional technical assistance. If Governor's office has not submitted a sufficient remedy within the 60-day period, OCR must notify the Governor that OCR has become responsible for securing compliance. If at any time the Governor's office notifies OCR that voluntary compliance cannot be achieved, OCR must document this decision in writing and initiate formal compliance actions.⁵⁶¹

According to the regional manager in OCR Region IX, there is a limit to how much OCR can delegate to State agencies, since their civil rights offices over the past several years have suffered worse cutbacks than has OCR headquarters.⁵⁶² Staff in Region I have tried to ensure that State recipients understand their responsibilities to comply with civil rights laws. Region I established a written memorandum of agreement with each State in the region, with respect to the State's block grant liaison's understanding of the

⁵⁵³ Halverson interview, p. 5.

⁵⁵⁴ 28 C.F.R. § 42.410 (1998); USCCR, *Federal Title VI Enforcement*, pp. 3, 88, 178. Each State receiving block grants enacted under the Omnibus Budget Reconciliation Act of 1981 is required to report on its programs. The OBRA requires States to report on the proposed use of block grant funds including: goals and objectives; activities to be supported, areas to be served, and "categories or characteristics" of the individuals to be served; and the criteria and method for fund distribution. 31 U.S.C. § 7303(a)(1)(A), (B), (C) (1994); *The New Wave of Federalism*, p. 4.

States are authorized to determine programmatic needs and the appropriate mix of services, set priorities, allocate funds, and establish oversight mechanisms. GAO, *Block Grants*, p. 1; HHS, *Review Team Report*, p. 23.

⁵⁵⁵ 47 Fed. Reg. 29,472, 29,478, 29,479 (1982).

⁵⁵⁶ Carpenter interview, pp. 3-4; USCCR, *Federal Title VI Enforcement*, pp. 3, 78; GAO, *Block Grants*, p. 1; *The New Wave of Federalism*, p. 4.

⁵⁵⁷ Carpenter interview, pp. 3-4; USCCR, *Federal Title VI Enforcement*, pp. 3, 78, 155.

⁵⁵⁸ Marcella Haynes, executive director, OCR Block Grant Task Force, memorandum to Betty Lou Dotson, director, OCR, HHS, re: block grant procedures, Sept. 22, 1982, p. 2 (hereafter cited as OCR, Block Grant Procedures); GAO, *Block Grants*, p. 27; PSPS interview, pp. 18-22 (statement of Haynes); Haynes interview, pp. 2-3. See also Edward Mercado, director, OCR, HHS, memorandum to Schuyler Baab, Deputy Under Secretary for Intergovernmental Affairs, re: role of regional officials in block grant matters, June 18, 1991, p. 1.

⁵⁵⁹ OCR, CRM, pp. 52-54.

⁵⁶⁰ OCR, Block Grant Procedures, p. 4; OCR, CRM, p. 53.

⁵⁶¹ OCR, CRM, p. 53.

⁵⁶² Pollack interview, p. 10.

nondiscrimination provisions of the 1981 OBRA, such as the responsibility to negotiate compliance in a State agency (within 60 days) that has discriminated on the basis of race, color, national origin, sex, disability, or religion in HHS block grant programs.⁵⁶³

Several States indicated to the Commission that they had not had any findings of violation forwarded to them from OCR, or could not recall any complaints being forward to them.⁵⁶⁴ Correspondence from two States indicated that OCR had conducted investigations and/or compliance reviews in their States. However, these States could provide little information on these cases.⁵⁶⁵ Such responses indicate a lack of consistent communication between OCR and the States and a failure to maintain information on civil rights violations.

Methods of Administration

Because Federal funding agencies ultimately are accountable for ensuring nondiscrimination in State-administered programs, HHS must monitor the quality of civil rights compliance and enforcement conducted by its recipients and

provide assistance whenever necessary.⁵⁶⁶ As such, States are required to develop and submit methods of administration (MOA) that describe how the State will enforce civil rights requirements within its block grant programs.⁵⁶⁷ Each application submitted by a State or State agency for participation in an HHS-funded continuing State program must include a statement providing a description of the MOA sufficient to give the Department official reasonable assurance that the applicant and all recipients will be in compliance with title VI.⁵⁶⁸

Developing and Revising Methods of Administration. OCR headquarters has not provided specific recommendations for developing methods of administration since 1979, before the introduction of block grants.⁵⁶⁹ However, some OCR regional offices have implemented recent initiatives to assist State agencies in developing their methods of administration.⁵⁷⁰ Some OCR regional offices are more involved with States and MOA issues than others.

In February 1996, the regional manager in Region VI wrote to State agencies informing them of their responsibility under title VI to develop and maintain MOA. The regional office enclosed MOA guidance so that each State agency would develop MOA that assured both the State agency and its subrecipients would

⁵⁶³ Caroline J. Chang, regional manager, Region I, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 12, 1999 (re: response to information request), p. 5 (hereafter cited as OCR Region I, Response to Information Request). See, as an example of a Region I memorandum of agreement, Caroline J. Chang, regional manager, Region I, OCR, HHS, "Memorandum of Agreement Between the State of Maine and the U.S. Department of Health and Human Services," pp. 1-2 (hereafter cited as OCR Region I, Memorandum of Agreement).

⁵⁶⁴ See, e.g., Douglas E. Bryant, commissioner, South Carolina Department of Health and Environmental Control, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 23, 1999 (re: information for health care report), p. 3; Lou Ellen Fairless, director of Health, Ohio Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 16, 1999 (re: information for health care report), p. 2; Murray G. Sagsveen, State health officer, North Dakota Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 15, 1999 (re: information for health care report), enclosure, p. 3; Carl T. Gutierrez, Governor of Guam, letter to Mireille Zieseniss, USCCR, Mar. 15 (re: information for health care report), enclosure, p. 1.

⁵⁶⁵ Mike Johanns, Governor, State of Nebraska, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 16, 1999 (re: information for health care report), enclosure, p. 3; George W. Bush, Governor, State of Texas, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 2, 1999 (re: information for health care report), enclosure, p. 4.

⁵⁶⁶ USCCR, *Federal Title VI Enforcement*, pp. 3, 178.

⁵⁶⁷ 45 C.F.R. § 80.4(b)(2) (1998).

⁵⁶⁸ *Id.* See also 28 C.F.R. § 42.410 (1998); GAO, Block Grants, p. 8.

⁵⁶⁹ See HHS, OCR, *Title VI Policy Compendium, 1965-1985*. OCR developed a general policy guideline based on its December 13, 1979, response to an inquiry from the Division of Standards and Policy Development concerning a letter of finding of noncompliance with title VI by the Arizona Department of Health Services. Overall, OCR suggested that the LOF should request that the State agency's MOA be amended, to reflect that the agency ensures that (a) the health needs of minorities are identified and are met as effectively as are those of nonminorities; and (b) no one is denied medical care or other health services (including access to programs of patient health education) or receives different health care services because of his/her limited English speaking ability. Burton M. Taylor, director, Division of Standards and Policy Development, memorandum to Floyd Pierce, director, OCR, Region IX, Dec. 13, 1979 (re: Arizona Department of Health Services LOF, case #09-79-7005), pp. 1-2 (hereafter cited as Taylor Memo).

⁵⁷⁰ O'Brien and Mackey interview, pp. 7-8 (statement of O'Brien).

comply with civil rights statutes.⁵⁷¹ OCR Region VI provided technical assistance to States in the process of updating their MOA, and advised the States that MOA should be revised if they needed to include coverage under section 504 or be made compatible with changes in the structure and leadership of various State agencies.⁵⁷²

Region VIII has a one-page comprehensive "methods of administration plan" on OCR's requirement that each State agency adopt and implement formal MOA that addresses several provisions that State agencies must include in their MOA, including civil rights responsibilities assigned to agency staff and vendors, procedures for maintaining compliance in all programs, nondiscrimination policies, and strategies for receiving and processing complaints alleging discrimination.⁵⁷³ Region X disseminates similar MOA guidelines to its State recipients.⁵⁷⁴

In 1998 Region I reviewed the status of each State's MOA, and identified State agencies for further action on MOA agreements.⁵⁷⁵ However, despite Region I's intention to monitor State recipients' compliance more effectively through assisting States in developing MOA, the region has not produced any procedures that are regularly given to State block grant recipients with respect to their methods of administration.⁵⁷⁶

⁵⁷¹ See, e.g., Ralph D. Rouse, Jr., regional manager, Region VI, letter to Tom Dalton, director, Arkansas State Department of Health and Human Services, Feb. 12, 1996 (re: developing MOA) (hereafter cited as OCR Region VI, MOA letter).

⁵⁷² Ralph D. Rouse, Jr., regional manager, Region VI, OCR, HHS, memorandum to Ron Copeland, associate deputy director, Office of Program Operations, Apr. 3, 1996 (re: Quarterly Significant Activities Report (SAR) for second quarter), pp. 12-13 (hereafter cited as OCR Region VI, Second Quarter 1996 SAR).

⁵⁷³ Office of the Regional Manager, Region VIII, OCR, HHS, "Methods of Administration Plan," no date (hereafter cited as OCR Region VIII, "MOA Plan").

⁵⁷⁴ OCR Region X EOS interview, pp. 15-16.

⁵⁷⁵ OCR Region I, FY 1998 AOP; Caroline Chang, regional manager, Region I, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Oct. 7, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of September 1998), p. 5; Caroline Chang, regional manager, Region I, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Nov. 4, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of October 1998), p. 3.

⁵⁷⁶ OCR Region I, Response to Information Request, p. 5. When asked by OCRE to provide a copy of all procedures/guidelines given to State agencies that operate block

Similarly, the regional manager for Region IV reported that the region does not have standardized MOA guidelines, because each agency and program is different. Regional staff do, however, assist State agencies upon request and help them address civil rights issues in their policies and programs. Thus, although Region IV has no official MOA guidelines, technical assistance is provided on an ad hoc basis.⁵⁷⁷

OCR Region V staff also have been assisting States in updating their MOA so that they are applicable to all HHS jurisdictions and not just title VI.⁵⁷⁸ Region III focused its outreach activities between 1994 and 1998 exclusively on MOA issues. The region provided guidelines to each of its States in developing MOA that were to be included in their respective State plans.⁵⁷⁹ Region VI established a comprehensive MOA template, similar to that of Region III.⁵⁸⁰ However, Region VII and Region IX have not published any procedures or guidelines to assist State block grant recipients in developing their

grant programs, Region I replied that it had no such documents. *Ibid.*

⁵⁷⁷ Marie Chretien, regional manager, Region IV, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 1, 1999 (re: Response to Information Request), p. 4 (hereafter cited as OCR Region IV, Response to Information Request); OCR Region IV EOS interview, p. 7.

⁵⁷⁸ Charlotte Irons, regional manager, Region V, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Apr. 7, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of March 1998), 1998, p. 3 (hereafter cited as OCR Region V, March 1998 SAR); Charlotte Irons, regional manager, Region V, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Sept. 3, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of August 1998), p. 2 (hereafter cited as OCR Region V, August 1998 SAR); and Charlotte Irons, regional manager, Region V, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, Oct. 13, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of September 1998), p. 2 (hereafter cited as OCR Region V, September 1998 SAR).

⁵⁷⁹ Paul Cushing, regional manager, Region III, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 11, 1999 (re: Response to Information Request), pp. 3, 6, and attachment, "Methods of Administration" (hereafter cited as OCR Region III, Response to Information Request).

⁵⁸⁰ OCR Region VI, Response to Information Request, attachment 4, "Methods of Administration"; OCR Region VI EOS interview, p. 14 (statement of Wilson).

MOA.⁵⁸¹ Further, OCR headquarters does not have an MOA model. According to the director of PSPS, model MOA would explain the particular data that States use to demonstrate that States and their subrecipients comply with title VI and the specific strategies States implement to monitor and enforce their recipients' compliance.⁵⁸² According to the director of PSPS, some HHS OCR regional offices, such as Region I, have established and disseminated model methods of administration.⁵⁸³

Evidence provided by States reflects OCR's uneven attention to providing assistance in the development and revision of MOA. Many of the States that provided information to the Commission noted that OCR had not provided guidance in developing MOA.⁵⁸⁴ However, one State noted

⁵⁸¹ John Halverson, regional manager, Region VII, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 11, 1999 (re: Response to Information Request), p. 11 (hereafter cited as OCR Region VII, Response to Information Request); Ira Pollack, regional manager, Region IX, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 15, 1999 (re: Response to Information Request), p. 5. (hereafter cited as OCR Region IX, Response to Information Request). Both Region VII and Region IX reported to OCRE that they had not provided any other manuals, guidelines, procedures, memoranda, etc., to assist State agencies that administer HHS-funded programs. *Ibid.* The Region VII EOS staff mentioned in an interview with OCRE that the region does not automatically review each State agency's MOA on a systematic basis. See OCR Region VII EOS interview, p. 8.

⁵⁸² Haynes interview, p. 6.

⁵⁸³ OCR Region I, FY 1998 AOP; PSPS interview, pp. 24, 26 (statement of Haynes).

⁵⁸⁴ See, e.g., John R. Lumpkin, director of Public Health, Illinois Department of Public Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 11, 1999 (re: information for health care report), enclosure, p. 6 (hereafter cited as Illinois letter); John H. Morse, Secretary for Health Services, Commonwealth of Kentucky, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 18, 1999 (re: information for health care report), p. 4; N. Warren Bartlett, director, Offices of Health Data and Program Management, Department of Human Services, State of Maine, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 18, 1999 (re: information for health care report), p. 3; Gary K. Weeks, director, Department of Human Resources, State of Oregon, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 12, 1999 (re: information for health care report), enclosure, pp. 8, 12; Edward M. Cahill, director, Bureau of Budget Management, State of New York Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 26, 1999 (re: information for health care report), p. 4; Carolyn

that OCR provided staff with a detailed guide for developing MOA and identified one OCR staff person who "was extremely helpful in addressing Department questions and concerns."⁵⁸⁵ OCR also provided assistance on MOA and developing a civil rights plan during the fall of 1998, when OCR staff visited the Utah Department of Health to obtain information on managed care organizations in the area.⁵⁸⁶ Nonetheless, the inconsistent approach to providing assistance to States in the development of methods of administration and the lack of OCR headquarters oversight suggest a disregard for ensuring State compliance with civil rights laws. OCR has neglected to clearly inform States' of their responsibilities regarding civil rights issues. States cannot be expected to ensure civil rights compliance without the assistance of a Federal civil rights enforcement agency, such as HHS.

OCR Reviews of State Recipients' Methods of Administration. OCR does not routinely review each State's activities.⁵⁸⁷ Further, there is no requirement that States revise and resubmit MOA unless an issue is covered by a compliance review or investigation.⁵⁸⁸ Although a State's methods of administration are among the criteria available to OCR to assess a particular State's compliance performance, OCR headquarters has not effected any cooperative agreements or memoranda of understanding with State agencies in order to coordinate effective civil rights enforcement. Similarly, although HHS requires its State recipients to submit MOA, OCR headquarters does not provide direct guidance to each State on preparing MOA, nor does OCR monitor States' adherence to such proce-

O. Maggio, director, State of Louisiana, Department of Health and Hospitals, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 22, 1999 (re: information for health care report), enclosure, p. 8.

⁵⁸⁵ J.R. Nida, M.D., commissioner of Health, Oklahoma State Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 8, 1999 (re: information for health care report), enclosure, p. 1.

⁵⁸⁶ Rod L. Beit, executive director, Utah Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 19, 1999 (re: information for health care report), pp. 4-5 (hereafter cited as Utah letter).

⁵⁸⁷ GAO, *Block Grants*, p. 8; PSPS interview, pp. 19-20 and 26-28 (statement of Haynes); OCR Region VIII EOS interview, p. 9.

⁵⁸⁸ OCR Region VIII EOS interview, p. 9.

dures.⁵⁸⁹ OCR headquarters also does not direct regional offices to review their respective State recipients' methods of administration on any particular timetable.⁵⁹⁰

The HHS regions vary in their performance with respect to monitoring States' MOA.⁵⁹¹ For instance, some regions attempt to specify that State recipients address title VI, title IX, section 504, ADA, and other civil rights statutes in their respective MOA to make them all encompassing.⁵⁹² Some regions stipulate that a State revise and submit its MOA if agency officials change or a State reorganizes such that the State and its programs are no longer compatible with the contents of its MOA.⁵⁹³ For new programs or expansions of existing programs, regional offices generally require States in their geographical region to submit updated methods of administration for review. In contrast, regional offices do not usually require a State block grant recipient to revise and resubmit its methods of administration if there is no change in the State's administration or provisions of the block grant program.⁵⁹⁴

Staff in Region X, for instance, examine State recipients' methods of administration on a revolving basis, so that each State has its MOA reviewed about every 3 or 4 years. States such as Alaska, which have fewer recipient health care agencies, tend to have their agencies' MOA reviewed more frequently.⁵⁹⁵ However, a complaint about a particular State agency, or a change in that agency's programs or structure, can trigger the need for OCR to examine that agency's MOA to determine its most recent compliance policies. Similarly, Region VI staff reported that they expect to review State agencies' MOA because

many of the agencies have undergone numerous structural changes, and the region wants the MOA to be consistent with the new structures.⁵⁹⁶

In contrast, Region IV staff stated that the region is in need of reviewing State agencies' MOA, since many programs and program administrators have changed. Currently, Region IV reviews States' MOA haphazardly, because of a lack of staff.⁵⁹⁷ Similarly, Region VIII does not routinely review State agencies' MOA and does not require the agencies to revise and resubmit the document unless an issue arises during a compliance review or complaint investigation.⁵⁹⁸

Again, OCR's efforts in reviewing MOA are inconsistent. Compliance reviews with regard to MOA are done in haphazard fashion, with some States being reviewed while others are not. Further, headquarters OCR is not involved with MOA issues and provided little guidance to the regions or to State recipients on the development and administration of methods of administration.

OCR Efforts to Monitor State and Local Agencies' Compliance

The director of PSPS said that civil rights staff attempt to collect, analyze, and maintain data; conduct preaward desk audits and onsite compliance reviews; conduct postaward desk audits, limited-scope reviews, and onsite compliance reviews; and investigate complaints in the same manner in block grant programs as they do in other programs.⁵⁹⁹ In addition, equal opportunity specialists reported that there were no specialized procedures for investigations related to block grant programs.⁶⁰⁰ Furthermore, when an OCR regional office conducts a compliance review of a State recipient, the review does not just cover one HHS program, such as a block grant program. Rather, OCR will investigate multiple programs to determine if a civil rights

⁵⁸⁹ USCCR, *Federal Title VI Enforcement*, pp. 9, 232; PSPS interview, p. 23 (statement of Haynes).

⁵⁹⁰ PSPS interview, pp. 24, 26 (statement of Haynes).

⁵⁹¹ *Ibid.*, pp. 22–26; O'Brien and Mackey interview, pp. 7–9; OPO interview, pp. 43–45 (statement of Mackey).

⁵⁹² PSPS interview, p. 22 (statement of Haynes); OCR Region V, March 1998 SAR, p. 3; OCR Region V, August 1998 SAR, p. 2; OCR Region V, Sept. 1998 SAR, p. 2; Jesse Berain, director, Idaho Commission on Aging, letter to Chisato Kawabori, regional program director, Region X, Aug. 7, 1995 (re: enclosed methods of administration).

⁵⁹³ PSPS interview, pp. 23–24 (statement of Haynes). *See, e.g.*, OCR Region VI, Second Quarter 1996 SAR, pp. 12–13; OCR Region X EOS interview, p. 15 (statement of Braun).

⁵⁹⁴ PSPS interview, pp. 23–26 (statement of Haynes).

⁵⁹⁵ OCR Region X EOS interview, p. 15 (statement of Plymouth).

⁵⁹⁶ George Bennett, Sandra Brumly, and Delores Wilson, equal opportunity specialists, Region VI, OCR, HHS, telephone interview, Feb. 2, 1999, p. 15 (statement of Bennett) (hereafter cited as OCR Region VI EOS interview).

⁵⁹⁷ OCR Region IV EOS interview, p. 7.

⁵⁹⁸ OCR Region VIII EOS interview, p. 9.

⁵⁹⁹ Haynes interview, pp. 3, 7.

⁶⁰⁰ OCR Region X EOS interview, p. 16; OCR Region IV EOS interview, p. 7; OCR Region VIII EOS interview, p. 9.

violation exists within a State agency that receives HHS funds.⁶⁰¹

HHS OCR's published block grant procedures reflect that OCR is authorized to conduct compliance reviews and investigate complaints of discrimination in State-administered programs.⁶⁰² However, as of June 1999, the Department had not implemented an effective monitoring system to ensure that States meet their own title VI compliance responsibilities in block grant programs, or ensure that States sufficiently monitor and enforce compliance by their respective subrecipients. The States have various methods for monitoring their subrecipients, which include financial audits, onsite reviews, and the collection of assurance forms.⁶⁰³ Further, it appears as if OCR has provided little guidance to States on methods to monitor recipients and ensure compliance with civil rights statutes.⁶⁰⁴

OCR does not have a systematic process to review States' title VI and title IX compliance policies, programs, and activities on a regular basis; it does not require State grantees to report their procedures to assess, achieve, and maintain their own compliance with civil rights policies and enforce compliance among their subrecipients; and it does not evaluate States' and subrecipients' civil rights compliance performance or review the quality of States' efforts to

monitor their respective subrecipients and assess/enforce their compliance with title VI and title IX.⁶⁰⁵ The OCR regional offices, not headquarters, are responsible for overseeing and monitoring State agencies' compliance with civil rights statutes and the nondiscrimination provisions in block grant statutes, and ensuring that the States evaluate and enforce their respective subrecipients' compliance with civil rights policies and deliver health care services in a nondiscriminatory manner.⁶⁰⁶

OCR headquarters does not direct regions to collect States' data on civil rights compliance procedures at specific time intervals. States tend to submit reports to their regional offices before an investigation or compliance review, but not on a regular basis and not to OCR headquarters.⁶⁰⁷ Although OCR does not collect States' data on title VI compliance procedures and strategies to enforce civil rights laws on a routine basis, State agencies must submit such data to HHS upon request.⁶⁰⁸ Nevertheless, OCR headquarters does not specify the particular reporting elements that State agencies must provide in progress reports to the regions, strategies to be used to comply with civil rights policies and procedures and enforce their respective subrecipients' compliance, or the frequency with which States must submit compliance/progress reports to the regional offices.⁶⁰⁹ Thus, States are collecting a wide array of data, but it is not being used for, or may not be relevant to, civil rights compliance.⁶¹⁰ Consequently, the Commission is

⁶⁰¹ Haynes interview, p. 7.

⁶⁰² PSPS interview, pp. 17, 21 (statement of Haynes); OCR, Block Grant Procedures.

⁶⁰³ For example, the State of Alaska requires assurances of compliance with civil rights statutes, conducts onsite reviews, and reviews quarterly reports. Peter M. Nakamura, director, Department of Health and Social Services, State of Alaska, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 22, 1999 (re: information for health care report), p. 2 (hereafter cited as Alaska letter). However, the State of Mississippi stated: "Subrecipients are required to provide signed agreements to comply to all relative laws, such as the Civil Rights Act of 1964. In addition, the agency maintains records of all clients served and they are available for review upon request." David M. Buchanan, director, Office of Policy and Planning, Mississippi State Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 18, 1999 (re: information for health care report), enclosure, p. 1 (hereafter cited as Mississippi letter).

⁶⁰⁴ See, e.g., Alaska letter, p. 2; Illinois letter, enclosure, p. 6; Mississippi letter, enclosure, p. 1; Carlessia A. Hussein, director, State of Maryland Department of Health and Mental Hygiene, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 1, 1999 (re: information for health care report), enclosure, p. 4.

⁶⁰⁵ USCCR, *Federal Title VI Enforcement*, pp. 3, 232, 246; PSPS interview, pp. 26–27 (statement of Haynes).

⁶⁰⁶ PSPS interview, pp. 27–28 (statement of Haynes). According to OCR OPO staff, "every thing we (OCR) do is at the regional level." See OPO interview, p. 48 (statement of Mackey).

⁶⁰⁷ PSPS interview, p. 27 (statement of Haynes).

⁶⁰⁸ Haynes interview, p. 6. See also 45 C.F.R. § 80.6(b) (1998).

⁶⁰⁹ PSPS interview, pp. 27–28 (statement of Haynes).

⁶¹⁰ For example, the State of New Mexico Department of Health stated: "Most programs in the Public Health Division collect basic demographic data, i.e., race, ethnicity, gender, and age and also geographic location. The Division is moving toward an integrated database to facilitate sharing of information and standardization of data collection between all applicable programs in the Division." J. Alex Valdez, Secretary, State of New Mexico Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 12, 1999 (re: information for health care report), p. 2. Similarly, the State of Utah re-

concerned that State agencies' requirements to report particular elements (and level of detail) with respect to their procedures to comply with civil rights and oversee/enforce their subrecipients' compliance and submit compliance reports to their respective regional offices at particular time intervals would vary across HHS regions—resulting in an obvious lack of uniformity in the content and format as well as frequency of States' reporting requirements.

Overall, HHS OCR regional offices conduct limited activities with respect to assessing and enforcing States' and their subrecipients' compliance with title VI, especially in the context of health care programs. The director of OCR's Policy and Special Projects Staff acknowledges that HHS regional offices lack consistent, effective procedures to monitor procedures of their respective recipient State agencies.⁶¹¹ Although various regional initiatives may relate to oversight and monitoring of State recipients, the program elements and motives do not seem to stress the need for OCR to ensure that States: (a) understand the provisions of civil rights statutes, (b) understand how discrimination can arise in the delivery of health care service and research programs, (c) are aware of their compliance responsibilities, and (d) have the skills and resources to assess subrecipients' efforts to

ported several programs that collect and report data on race, ethnicity, and gender, such as: Women's Health in Utah, Health Status in Utah by Race and Ethnicity, Utah's Healthy People 2000: Health Status Indicators by Race and Ethnicity, Utah Health Status Survey on Ethnic Populations, and Indian Health Care. Utah letter, pp. 4–5. In addition, the Tennessee Department of Health "operates an integrated computerized patient system in all 95 counties of Tennessee. Data are routinely collected and reported by program by clinic to reflect gender/racial/ethnic demographics. . . . data [are] compiled concerning specific minority segments in Tennessee. The combination of patient data and population data serve as the baseline to determine if at risk populations are being targeted and served appropriately." Fredia S. Wadly, M.D., State of Tennessee Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: information for health care report), enclosure, p. 2.

Comparatively, some States appear to collect data only for certain programs. For example, the State of West Virginia collects data on race and ethnicity for mortality, morbidity, and risk behaviors. Joan E. Ohl, Secretary, State of West Virginia Department of Health and Human Resources, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: information for health care report), enclosure.

⁶¹¹ PSPS interview, p. 19 (statement of Haynes).

administer health care programs in a nondiscriminatory manner. In fact, some regions do not maintain relationships with State grantees of block grant programs. As Governors have changed over the years and as block grant programs have evolved, attention to State recipients has diminished.⁶¹²

Moreover, according to the director of PSPS, OCR does not have the manpower to evaluate States' and subrecipients' compliance responsibilities on a regular basis.⁶¹³ Consequently, OCR headquarters does not routinely ask regional offices to evaluate how effectively and sufficiently States track the flow of HHS funds from State agencies to their respective subrecipients, comply with civil rights statutes, and monitor and enforce their subrecipients' compliance with civil rights statutes. In addition, headquarters does not require regional offices to evaluate subrecipients' compliance with civil rights statutes.⁶¹⁴

According to staff in Region VII, OCR's oversight of State agencies is sporadic. Region VII does not disseminate a data collection instrument to State recipients on a systematic basis to assess their own and their subrecipients' compliance with civil rights statutes.⁶¹⁵ Similarly, Region VIII EOS reported that State agencies "have no reporting requirements."⁶¹⁶ The regional manager in Region II reported that race, ethnicity, and gender data are not collected from State recipients "as frequently as should be the case."⁶¹⁷ In fact, it seems to not be a practice among OCR regions to disseminate a data request to State agencies on a consistent basis for elements such as strategies to ensure their own and enforce their subrecipients compliance.⁶¹⁸ Several OCR headquarters and regional staff reported that data related to assessing a recipi-

⁶¹² *Ibid.*, pp. 19–20 (statement of Haynes).

⁶¹³ Haynes interview, p. 6.

⁶¹⁴ *Ibid.*

⁶¹⁵ See OCR Region VIII EOS interview, p. 8 (statement of Kemp).

⁶¹⁶ *Ibid.*, p. 9.

⁶¹⁷ Carter interview, p. 8.

⁶¹⁸ PSPS interview, pp. 19–20, 26–27 (statement of Haynes); Haynes interview, p. 6; Chang interview, p. 12; Carter interview, p. 8; Chretien interview, p. 12; Halverson interview, p. 8; Pollack interview, pp. 9–10; OCR Region VII EOS interview, p. 8 (statement of Kemp); and OCR Region VIII EOS interview, p. 9.

ent's compliance with civil rights statutes are collected only during a complaints investigation or compliance review.⁶¹⁹

OCR states that it has not had to refer a finding of a violation of a civil rights statute to a Governor.⁶²⁰ In the early 1980s, HHS Regions III, IV, and VII did receive complaints of discrimination in State-administered block grant programs, which led to letters of warning being issued to the appropriate Governors.⁶²¹ However, none of the complaints investigations or any more recent HHS compliance review of a block grant program has led to a letter of finding.⁶²²

According to an investigator in Region X, determining the number of complaints that arise specifically in the context of a particular health care block grant program can be difficult due to OCR's lack of facility to track the multiple HHS funding sources allocated to any one State entity.⁶²³ These recipients would receive their allocations from HHS as one "lump sum" rather than in distinct appropriations from each program. Because State agencies receive funds from multiple HHS sources, it is difficult for Region X staff to determine readily the particular health care program in which a complaint was generated.⁶²⁴

EOS staff in Region II stated that they also have problems tracking Federal financial assistance.⁶²⁵ The region can identify the State entities that receive HHS funds overall, but it cannot decipher these funds by program.⁶²⁶ Region VIII also reported that in some States, money for different programs is "lumped together," which can potentially hinder OCR's assessment of State agencies' efforts to sufficiently and effectively track and oversee the distribution of block grant funds to subrecipients.⁶²⁷ The regional

manager from Region I said that many HHS recipients receive funds from multiple operating divisions and all the information OCR may have is the total amount of HHS funds allocated to those recipients.⁶²⁸

HHS has taken several steps that may lead to improved monitoring of States' title VI compliance. In 1994 OCR expected to develop partnerships with recipient State agencies and establish a civil rights training program for State and local agency staff on ways in which they can prevent discrimination.⁶²⁹ As a result, regional offices include several State-related activities in their annual plans.⁶³⁰ In addition, State officials have approached regional OCR offices for technical assistance on OCR policies.⁶³¹ This was particularly the case when States received OCR's policy guidance on the Multiethnic Placement Act (MEPA).⁶³² For example, for FY 1998, Region I planned a technical assistance session on the interethnic adoption provisions of the Small Business Job Protection Act of 1996⁶³³ to be given to various State agencies in its region.⁶³⁴

Assessment of Interaction Between State Recipients and HHS OCR

Overall, interaction between OCR and State agencies has increased, but such interaction has not necessarily been fostered by block grant programs.⁶³⁵ Rather, OCR's 1994 Strategic Plan,

⁶¹⁹ PSPS interview, p. 27 (statement of Haynes); OMPE interview, p. 7 (statement of Melov); Chang interview, p. 12; Chretien interview, p. 12; Halverson interview, p. 8; and Pollack interview, pp. 9–10.

⁶²⁰ GAO, *Block Grants*, p. 28; and PSPS interview, pp. 20–21 (statement of Haynes).

⁶²¹ PSPS interview, pp. 21–21 (statement of Haynes).

⁶²² *Ibid.*

⁶²³ OCR Region X EOS interview, p. 16 (statement of Plymouth).

⁶²⁴ *Ibid.*

⁶²⁵ OCR Region II EOS interview, p. 5.

⁶²⁶ *Ibid.*

⁶²⁷ OCR Region VIII EOS interview, p. 9

⁶²⁸ Chang interview, p. 2.

⁶²⁹ Dennis Hayashi, director, OCR, HHS, letter to Frederick Isler, acting assistant staff director, Office of Civil Rights Evaluation, USCCR, Nov. 14, 1994, pp. 2–3 (hereafter cited as Hayashi, Title VI Plans). A 1993 HHS telephone survey to selected State administrators of HHS block grant programs, including the maternal and child health services block grant program and the alcohol and drug abuse and mental health services block grant programs, revealed that none of them had received any technical assistance or training from HHS OCR. See HHS, *Review Team*, p. 23.

⁶³⁰ Hayashi letter, Title VI Plans, p. 5.

⁶³¹ OPO interview, pp. 43–44 (statement of Mackey).

⁶³² *Ibid.*, p. 44 (statement of Mackey). See HHS, OCR, and HHS, Administration for Children and Families, Office for Civil Rights, "Policy Guidance on the Use of Race, Color, National Origin as Considerations in Adoption and Foster Care Placements," undated.

⁶³³ Pub. L. No. 104–188, title I, § 1808(c), 110 Stat. 1755, 1904 (codified at 42 U.S.C. § 1996b(1)–(3) (Supp. II 1996)).

⁶³⁴ OCR Region I, FY 1998 AOP.

⁶³⁵ PSPS interview, pp. 28–29 (statement of Haynes).

which has proposed that OCR work more closely, frequently, and effectively with State agencies, has provided the impetus for State recipient-OCR interaction.⁶³⁶ In general, OCR's interaction with recipient State agencies occurs on the regional rather than the headquarters level.⁶³⁷ According to staff in Region X, interaction with State agencies has been consistent since 1994, and has not necessarily increased or decreased since this time.⁶³⁸ In contrast, the regional manager in Region IX mentioned that the region does not monitor State agencies very closely, but the region staff will work with State agencies to resolve complaints that arise in their respective programs.⁶³⁹ OCR, as the civil rights enforcement agency of HHS, must ensure that State recipients and subrecipients comply with applicable civil rights provisions.

Technical Assistance, Outreach, and Education

Technical assistance is a tool with which Federal civil rights enforcement agencies can enhance their civil rights implementation and enforcement activities. It should be used as a strategy, in conjunction with other methods such as compliance reviews, to assist the agency in its responsibilities to inform the public of its rights to fair and equitable treatment under Federal civil rights mandates.

A review of the agency's dissemination of information about the civil rights laws it enforces shows the importance of technical assistance, and education and outreach in OCR's operations. Through these activities, OCR can inform applicants, communities, advocacy groups, recipients, participants, and beneficiaries of Department of Health and Human Services-funded programs' civil rights requirements. These efforts can ensure awareness and understanding of compliance with respect to the responsibilities these laws confer on health care providers. However, it appears from a review of OCR's technical assistance activities, the agency's efforts with respect

to title VI, Hill-Burton, and title IX are significantly weaker than their technical assistance efforts for the other statutes it enforces. As a result, actual and potential applicants and recipients may lack sufficient knowledge of title VI, Hill-Burton, and title IX compliance requirements to effectuate full compliance. Likewise, beneficiaries and participants in the affected communities may lack sufficient knowledge about these statutes' requirements to initiate complaints or otherwise pursue and protect their rights under these statutes.⁶⁴⁰

Within OCR, the Office of Program Operations and the regional offices conduct technical assistance and outreach activities.⁶⁴¹ OCR provides technical assistance to recipients of HHS funds to encourage voluntary compliance with the civil rights laws and regulations that the Department enforces. Technical assistance is made available through training, developing and disseminating compliance information, and by providing recipients, recipient groups, and State and local officials with guidance on how to comply voluntarily with applicable civil rights laws.⁶⁴² Technical assistance and outreach initiatives are undertaken with State and local governments, recipient and beneficiary organizations, and other advocacy groups to prevent and identify early any potential problems, and to initiate strategies to avoid or correct them.⁶⁴³ OCR seeks successful voluntary compliance in part through outreach initiatives to service providers and State and local recipients. Essentially, OCR views its technical assistance efforts as proactive measures that will help to alleviate and resolve civil rights compliance problems.⁶⁴⁴

Regulatory Requirements

DOJ's coordination regulations do not require Federal agencies to offer technical assistance to recipients of Federal financial assistance to help them comply with title VI and other civil rights statutes. Given the complexity of title VI requirements and the increasing tendency for Fed-

⁶³⁶ Ibid. See also HHS, OCR, "Strategic Plan," Dec. 16, 1994, pp. 1-22.

⁶³⁷ PPS interview, p. 19 (statement of Haynes).

⁶³⁸ OCR Region X EOS interview, p. 16 (statement of Braun).

⁶³⁹ Pollack interview, p. 10.

⁶⁴⁰ USCCR, *Federal Title VI Enforcement*, p. 245.

⁶⁴¹ OPO interview, p. 20 (statement of Shepperd).

⁶⁴² HHS, OCR, *FY 1997 Congressional Justification* (Appropriations Report), p. 19 (hereafter cited as OCR/HHS *FY 1997 Congressional Justification*).

⁶⁴³ Ibid.

⁶⁴⁴ See *ibid.*, p. 20.

eral agencies to delegate title VI compliance responsibilities to State and local recipient agencies, the need for agencies to develop comprehensive programs of technical assistance has become increasingly apparent.

DOJ's coordination regulations contain a section on "public dissemination of title VI information,"⁶⁴⁵ although the public outreach requirements for Federal agencies are limited. Federal agencies are required only to "make available" their title VI regulations and guidelines, and a similar requirement applies to State compliance programs.⁶⁴⁶ The coordination regulations also direct Federal agencies to require recipients, where feasible, to "display prominently in reasonable numbers and places posters which state that the recipients operate programs subject to the nondiscrimination requirements of title VI, summarize those requirements, note the availability of title VI information from recipients and the federal agencies, and explain briefly the procedures for filing complaints."⁶⁴⁷ In addition, they require Federal agencies and recipients to "include information on title VI requirements, complaint procedures and the rights of beneficiaries in handbooks, manuals, pamphlets and other material which are ordinarily distributed to the public to describe federally assisted programs and the requirements for participation by recipients and beneficiaries."⁶⁴⁸ Other than these requirements, the agencies are directed to ensure that such information is available in languages other than English.⁶⁴⁹

HHS' implementing regulations for title VI require that recipients are provided "assistance and guidance" to help them comply voluntarily with the law.⁶⁵⁰ This provision is important because the regulations also require recipients to notify participants, beneficiaries, and other interested persons of the provisions of title VI and how they apply to the recipient's program.⁶⁵¹ It is doubtful that recipients can comply with their title VI outreach responsibilities if they do not

have proper guidance and assistance in understanding the statute. Similarly, the Department's implementing regulations for the community service assurance under the Hill-Burton Act requires recipients to disseminate information on civil rights responsibilities through posted notices.⁶⁵² However, the notice only instructs patients who believe they have been discriminated against to contact OCR, and there is no address or telephone number provided on the notice.⁶⁵³ It is also questionable whether patients are aware that recipients are required to post notices concerning civil rights.

Extent of Technical Assistance Efforts

In its fiscal year 1998 budget submission to the Department, OCR identified title VI and section 504 as the two priority civil rights areas that would be the focus of its technical assistance activities.⁶⁵⁴ In this submission, OCR wrote that in conducting its civil rights compliance and outreach functions, it would "actively support" and undertake initiatives that would ensure that individuals would be treated in a nondiscriminatory manner by providers and/or facilities.⁶⁵⁵ OCR has conducted technical assistance and outreach for section 504. It also has developed initiatives for technical assistance and outreach on MEPA and LEP issues in the title VI context. However, a fully developed and implemented title VI outreach program has been almost nonexistent at headquarters and in the regional offices.

OCR staff attribute the decline in outreach activities, particularly for title VI, to the significant budgetary constraints OCR has faced for many years. For example, OCR's deputy director of the Program Development and Training Divi-

⁶⁴⁵ 28 C.F.R. § 42.405 (1998).

⁶⁴⁶ *Id.* § 42.405(a), (b).

⁶⁴⁷ *Id.* § 42.405(c).

⁶⁴⁸ *Id.*

⁶⁴⁹ *Id.* § 42.405(d).

⁶⁵⁰ 45 C.F.R. § 80.6(a) (1998). *See also* OPO interview, p. 21 (statements of Nelson and Shepperd).

⁶⁵¹ *Id.* § 80.6(d) (1998).

⁶⁵² *See id.* § 124.604(a), (b), (c) (1998); OPO interview, p. 21 (statement of Shepperd). The Hill-Burton notice does include a antidiscrimination clause: "The facility is not allowed to discriminate against a patient because of race, creed, color, national origin, or because a patient is covered by a program such as Medicaid or Medicare." OCR Region I, Response to Information Request, enclosure D, pp. 7-8.

⁶⁵³ OCR Region I, Response to Information Request, enclosure D, p. 8.

⁶⁵⁴ HHS, OCR, *FY 1998 Budget Submission to the Office of the Secretary/HHS* (no date), p. 2 (hereafter cited as *HHS/OCR, FY 1998 Budget Submission*). The emphasis on section 504 was discrimination against persons with HIV/AIDS.

⁶⁵⁵ *Ibid.*, p. 3.

sion said that currently OCR is not able to use advertising techniques, such as posters or publications, to educate the public about title VI.⁶⁵⁶ She explained that when there was adequate funding for advertising, OCR did have title VI posters. They were disseminated through the regional offices at conferences and during onsite visits. There also were brochures on every statute that included instructions on how to file a complaint.⁶⁵⁷ The deputy to the associate director also explained that OCR had exhibits and displays that were taken to conferences. However, because of limited resources, the exhibits are rarely used. According to her, the exhibits are “old and ragged,” and have not been used for a number of years.⁶⁵⁸

Budget constraints appear to have affected title VI and Hill-Burton technical assistance and outreach more than other statutes and initiatives. For example, while written technical assistance materials and information on title VI and Hill-Burton has been limited, in OCR’s 1998 pregrant data request package distributed to recipients, OCR included approximately 20 pages of detailed information on section 504. The section 504 attachment in the package includes a glossary, questions and answers, a notice of program accessibility, and a self-evaluation checklist.⁶⁵⁹ One staff person has acknowledged that very little has been done in technical assistance on title VI, and indicated that OCR is not mandated to perform technical assistance on Hill-Burton.⁶⁶⁰

Headquarters Activities

Although OCR has identified technical assistance priorities and made recommendations for specific activities, OCR headquarters does not perform nor does it require regional offices to perform a specified number or type of outreach

activity.⁶⁶¹ OCR staff therefore cannot specify the amount of staff time spent on technical assistance, outreach, and education activities.⁶⁶² For annual operating plans, OCR headquarters attempts to give the regional offices as much flexibility as possible in the allocation of resources for such activities. At the headquarters level, OCR has prepared guidance on LEP, welfare reform, and Hill-Burton, and solicited comments and suggestions from affected communities on this guidance as well as on the title VI survey, which was sent to advocacy groups and other interested parties.⁶⁶³ In addition, OCR has developed several fact sheets,⁶⁶⁴ which are available in languages other than English, including Hmong and Spanish. OCR tries to produce fact sheets in the predominant language of an area, although that is not always possible, given re-

⁶⁶¹ For example, the FY 1998 guidance for annual operating plans includes nine priorities, including adoption and foster care, LEP, managed care, technical assistance for caseworkers on civil rights and welfare reform, hospital services, other health care and social services delivery systems, Presidential/Secretarial initiative on race, departmental initiative on adult immunization and vaccine safety, title VI/title IX applied to federally conducted programs. Every region must conduct at least one compliance review and one outreach activity in each of the first four programmatic priorities. In addition, every region must plan review and outreach activities undertaken with facilities that are selected based on the title VI survey results. OCR, FY 1998 AOP guidance, pp. 1–2.

⁶⁶² OPO interview, p. 20 (statement of Copeland).

⁶⁶³ *Ibid.*, p. 24 (statement of Mackey). Many of these initiatives have been replicated at the regional level. *Ibid.*

⁶⁶⁴ The OCR fact sheets include “Know Your Civil Rights” which also tells beneficiaries how to file a complaint of discrimination; “Your Rights Under Title VI of the Civil Rights Act of 1964”; “Community Service Assurance Under the Hill-Burton Act”; “Your Rights Under the Age Discrimination Act”; “Your Rights as an Individual with Handicaps Under section 504”; “Your Rights as A Person with HIV Infection, AIDS, or Related Conditions”; “Adoption Fact Sheet”; and “The Multiethnic Placement Act (MEPA) Fact Sheet.” OCR also has Question and Answer fact sheets on civil rights, including one called “Office for Civil Rights—Frequently Asked Questions with Answers,” and another on the implementation of MEPA. All of the fact sheets can be accessed on the Internet. OCR also has a technical assistance fact sheet for the implementation of the temporary assistance for needy families which gives welfare providers and employees a one-page overview of the Federal civil rights laws that are enforced, including title VI. However, it does not provide detailed information on any of the laws discussed. See HHS, OCR, “Technical Assistance for Caseworkers on Civil Rights Laws and Welfare Reform,” draft, submitted by Kathleen O’Brien, special assistant, OCR, HHS, Apr. 13, 1999.

⁶⁵⁶ OPO interview, p. 21 (statement of Shepperd).

⁶⁵⁷ *Ibid.*

⁶⁵⁸ *Ibid.*, p. 22 (statement of Mackey).

⁶⁵⁹ Ronald G. Copeland, associate deputy director, Office of Program Operations, OCR, HHS, memorandum to regional managers, Regions I–10, Aug. 26, 1998. This package was developed and completed as the Automated Pregrant Review Data Request Project that became effective on October 1, 1998. The package of information about various OCR non-discrimination policies is to be distributed to recipients in the pregrant review data request.

⁶⁶⁰ OPO interview, p. 21 (statement of Shepperd).

source limitations.⁶⁶⁵ The fact sheets have not been updated for a number of years.⁶⁶⁶ The director of the Policy and Special Projects Staff in OCR indicated that OCR has not developed any new publications, including fact sheets, since the early 1990s.⁶⁶⁷ She explained that the primary reason for the reliance on fact sheets rather than more detailed brochures and publications is the lack of funds for such initiatives. She acknowledged that most of the fact sheets do need to be updated.⁶⁶⁸

The fact sheets do not clearly describe the role of OCR or provide sufficient information on civil rights issues. For example, the fact sheet on the Hill Burton Act summarizes the requirement for informing the public of a facility's community service obligations. However, the fact sheet neglects to explain what a Hill-Burton facility is, thus, it is not clear how a beneficiary would know if the services were being provided by a Hill-Burton facility. Further, it is uncertain if OCR sees that such notices are posted as required, and if such notices are meeting the language requirements set forth in the regulations.⁶⁶⁹

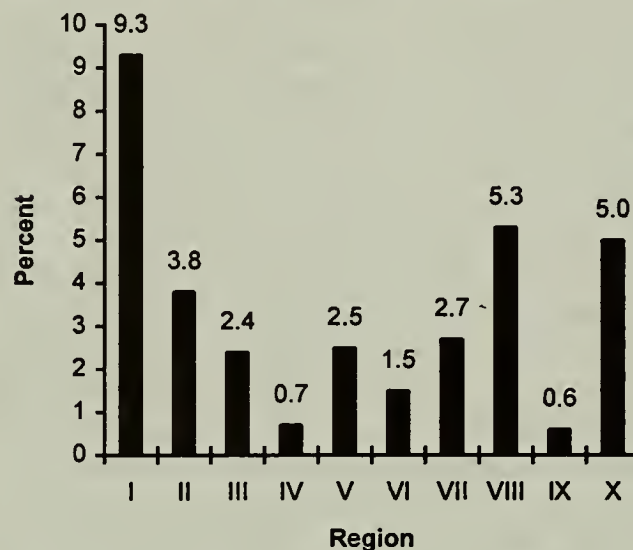
Overall, it appears as if headquarters OCR has little involvement with technical assistance, outreach, and education. With the exception of priorities set out in the annual operating plan, headquarters provides little guidance to the regions with respect to conducting technical assistance, outreach, and education programs. Further, headquarters produced no evidence of conducting an organized technical assistance program of its own. The Office of Program Operations, Voluntary Compliance and Outreach Division, has only two employees, suggesting the low priority of outreach and technical assistance within headquarters.⁶⁷⁰

Regional Activities

According to OCR, in conducting their respective outreach activities, the regional offices work

with advocacy groups and other interested parties on an ongoing basis. Other important aspects of the technical assistance efforts of the regional offices include memberships on boards

Figure 4.14
Voluntary Compliance and Outreach as a Percentage of Total Workload, FY 1998



SOURCE: U.S. Department of Health and Human Services, Office for Civil Rights, Case Activity Tracking System Database, FY 1998.

of key health care advocacy groups and task forces.⁶⁷¹

The 10 regional offices view the importance of technical assistance differently (see figure 4.14).⁶⁷² Technical assistance, outreach, and education accounts for anywhere from 9.3 percent of total workload (in Region I) to 0.06 percent of total workload (in Region IX). This uneven approach to civil rights enforcement results in different access to civil rights information for minority groups across OCR regions.

Who performs technical assistance, outreach, and education also varies from region to region. Technical assistance within regions is usually provided by the regional attorney and the equal opportunity specialists.⁶⁷³ In Region VIII, the

⁶⁶⁵ PSPS interview, p. 33 (statement of Haynes).

⁶⁶⁶ OPO interview, p. 21 (statement of Shepperd).

⁶⁶⁷ PSPS interview, p. 32 (statement of Haynes).

⁶⁶⁸ *Ibid.*, p. 33 (statement of Haynes).

⁶⁶⁹ HHS, OCR, Fact Sheet, "Community Service Assurance Under the Hill-Burton Act," August 1990.

⁶⁷⁰ HHS, OCR, "Position Management Control System, 09/13/98 thru 09/26/98," Oct. 10, 1998. See vol. II, chap. 2.

⁶⁷¹ OPO interview, p. 24 (statement of Mackey); OCR Region III, Response to Information Request, p. 3.

⁶⁷² See figure 4.14.

⁶⁷³ Jean Simonitsch, regional attorney, Region VII, OCR, HHS, telephone interview, Feb. 8, 1999, p. 4 (hereafter cited as Simonitsch interview); Geer interview, p. 3; OCR Region

regional manager assigns technical assistance, education, and outreach activities to the EOS, or an EOS can ask to do certain activities.⁶⁷⁴ In Region I, technical assistance is provided by all regional staff, including managers and attorneys.⁶⁷⁵ In Region II the regional manager performs most of the technical assistance, outreach, and education.⁶⁷⁶

Most of the education and outreach activities are requested by groups rather than initiated by the regional office.⁶⁷⁷ Technical assistance also can be part of a case settlement or resolution agreement.⁶⁷⁸ To implement these activities, some regional managers have taken responsibility for education and outreach mainly by attending or participating at conferences, meetings, or other forums sponsored by local groups.⁶⁷⁹ In Region VII, the regional manager said that his staff would like to conduct outreach and education, but the budget and their compliance work do not allow them to perform education and outreach functions at this time.⁶⁸⁰ The Region II manager stated that, because of resources, his office has been unable to cover areas of the region other than New York City. He noted that resources "have not allowed for a continuous, physical presence in areas throughout the region," and added, "Without a continuous, physical presence, you are soon forgotten."⁶⁸¹

In the past, when more resources were available for outreach, there was more contact with community organizations such as the Urban League and La Raza, as well as to beneficiaries and members of other racial and ethnic groups.⁶⁸² Case backlog and budget constraints

have hindered several regional offices from carrying out technical assistance activities for all its statutes and programs.⁶⁸³ Because of these barriers, OCR has been prioritizing its outreach and targeting specific groups for technical assistance. Regional staff have conducted their technical assistance, education, and outreach programs primarily in certain civil rights areas and HHS programs, such as section 504, managed care, adoption, Temporary Assistance to Needy Families (TANF), LEP, and mostly in the human social service areas rather than in the health care agencies.⁶⁸⁴

Other than guidelines for the annual operating plans, there are no standards for the provision of outreach, education, and technical assistance.⁶⁸⁵ Further, the regions have noted that training is needed in presentation skills and public speaking so that staff can more appropriately present information to various groups.⁶⁸⁶ There is no indication that regions have shared information and techniques for conducting technical assistance, outreach, and education, as was suggested in a 1992 report of the Office of Inspector General.⁶⁸⁷

Overall, regional offices have not made adequate efforts to disseminate title VI and Hill-Burton technical assistance information on civil rights compliance to stakeholders and to ensure that such information is widely accessible and visible to the public. Technical assistance appears to be provided on an ad hoc basis, addresses a limited number of issues, and is not conducted according to any standards or guide-

IV EOS interview, pp. 6-7; OCR Region IV EOS interview, p. 11 (statement of Bennett).

⁶⁷⁴ OCR Region VIII EOS interview, p. 7.

⁶⁷⁵ Linda Yuu-Conner and Peter Chan equal opportunity specialists, Region I, OCR, HHS, telephone interview, Feb. 23, 1999, p. 6 (hereafter cited as OCR Region I EOS interview).

⁶⁷⁶ Halverson interview, p. 7.

⁶⁷⁷ OCR Region I EOS interview, p. 6; Halverson interview, p. 7.

⁶⁷⁸ OCR Region IV EOS interview, p. 7.

⁶⁷⁹ Halverson interview, p. 7.

⁶⁸⁰ Ibid.

⁶⁸¹ Carter interview, pp. 5-6.

⁶⁸² OPO interview, p. 22 (statement of Mackey). In 1998 Region III staff participated in the La Raza National Conference, distributing information to participants through an information booth shared with the Health Care Financing

Administration. OCR Region III, Response to Information Request, p. 4.

⁶⁸³ For example, in FY 1994, because of case backlog, Region III limited its outreach activities to issues regarding methods of administration. See OCR Region III, Response to Information Request, p. 3.

⁶⁸⁴ Chretien interview, p. 11.

⁶⁸⁵ OCR Region IV EOS interview, p. 7.

⁶⁸⁶ HHS, OCR, "1998 Regional Training Needs," Mar. 12, 1998.

⁶⁸⁷ In 1992 HHS' Office of the Inspector General recommended that OCR determine whether technical assistance guides and methods developed in individual regions could be shared nationally; the OIG report stated that OCR "should explore methods that would enable them to share the expertise developed in one regional office with other regional office staff." HHS, Office of Inspector General, *Office for Civil Rights' Oversight of the Hill-Burton Program* (OEI-05-90-00261), August 1992, p. ii (hereafter cited as HHS/OIG, *Oversight of the Hill-Burton Program*).

lines. Further, technical assistance activities are not done evenly across the regions; staff do not have adequate training in teaching and presentation methods; and OCR's budget for outreach, education, and technical assistance activities is limited.

Title VI, Title IX, and Hill-Burton Technical Assistance and Education

Some of the regional offices indicated that they have conducted technical assistance on title VI specifically within the past 4 years. Region VII reported that during fiscal years 1995 and 1996, it partnered with the Missouri Department of Health to provide title VI technical assistance training to Missouri county health officials.⁶⁸⁸ Similarly, Region IX held an open forum to address title VI bilingual services in 1998.⁶⁸⁹ At the briefing, OCR staff presented case studies for discussion, a guidance memorandum on title VI prohibition against national origin discrimination, and guidelines for compliance of hospitals, nursing homes, and other facilities with title VI.⁶⁹⁰

However, many staff members stated that title VI outreach, education, and technical assistance activities are lacking. This is due in large part to OCR's failure to develop an outreach and education program targeted to minority communities, both urban and rural, that would ensure community members have sufficient information and guidance on their rights under these laws and on activities, such as compliance reviews and complaint investigations that OCR undertakes.⁶⁹¹

To illustrate, with respect to title VI and Hill-Burton, Region I reported that it does not regularly or routinely solicit comments from affected communities and recipients regarding title VI or any other civil rights statutes it enforces.⁶⁹² The regional office provides information to beneficiaries and communities on the extent of their civil rights and how to file a complaint. Title VI and Hill-Burton are included whenever general, oral presentations are made by staff.⁶⁹³ One re-

gional manager urged more outreach and education activities on title VI. She stated that the general lack of awareness among the public about title VI is a direct result of the failure to publicize it more vigorously.⁶⁹⁴ Title VI outreach efforts are primarily aimed at foster care or LEP issues.⁶⁹⁵

With respect to Hill-Burton technical assistance and outreach activities, one region reported that in 1996, it issued over 200 letters to hospital associations that have Hill-Burton facilities as members. These "outreach" letters were mailed to all of the States in the region to inform the facilities of their responsibilities under the act.⁶⁹⁶ This region also conducted a joint effort with hospital associations to inform recipients, such as hospitals that receive Hill-Burton funds, about their civil rights obligations under the community service assurance.⁶⁹⁷ In 1998 Region VIII held a briefing for advocacy groups on the Hill-Burton compliance reporting requirements.⁶⁹⁸ Few of the regions mentioned title IX in their discussions of technical assistance, outreach, and education activities they have conducted. One regional attorney stated that she did not recall having done any technical assistance for title IX or Hill-Burton.⁶⁹⁹ Another attorney stated that there is not much technical assistance provided on either title IX or Hill-Burton in her region.⁷⁰⁰

Outreach to Advocacy and Community Groups

Outreach to community groups varies across the regions. Region III, for example, has done extensive work in the Hispanic community.⁷⁰¹ Region III also has formulated outreach teams that target specific groups and organizations in

⁶⁸⁸ OCR Region VII, Response to information request, p. 7.

⁶⁸⁹ OCR Region IX, Response to Information Request, p. 4.

⁶⁹⁰ *Ibid.*, Package of Briefing Materials, divider #2.

⁶⁹¹ OCR Region I, Response to Information Request, p. 3.

⁶⁹² *Ibid.*

⁶⁹³ *Ibid.*, enclosure D.

⁶⁹⁴ Kyle-Holmes interview, p. 4.

⁶⁹⁵ See Golightly-Howell interview, p. 2.

⁶⁹⁶ OCR Region III, Response to Information Request, tab 11, tab 13.

⁶⁹⁷ OCR Region III, Response to Information Request, tab 13, Hill-Burton Training for OPDIVS and Presentation to OPDIVS, p. 4.

⁶⁹⁸ OCR Region VIII EOS interview, p. 8.

⁶⁹⁹ Golightly-Howell interview, p. 2.

⁷⁰⁰ Miyasato interview, p. 2.

⁷⁰¹ OCR Region III, Response to Information Request, pp. 3-4, tab 15. The public service announcement is in English and Spanish. It is brief and offers very little information about civil rights or what is meant by being discriminated against. See *ibid.*, tab 15.

LEP communities. There is a Hispanic Outreach Team and an Asian Outreach Team that work with organizations on outreach activities for their LEP clients.⁷⁰² For example, the Hispanic Outreach Team is working with the Spanish Catholic Center on outreach activities for Latinos; the Asian Outreach Team attends conferences that address the Cambodian and Vietnamese cultures.⁷⁰³

Region IX reported that it is in "regular and constant contact" with advocacy groups, community organizations, and recipients.⁷⁰⁴ The office said that most of these contacts are through conferences, meetings, and telephone calls. Staff "routinely" distribute fact sheets to the public, as well as information on their rights and how to file a complaint.⁷⁰⁵ The amount of external outreach and education varies from region to region. For example, while some regions have implemented a variety of initiatives with limited resources, other regions have not been so innovative with their outreach program.

Interagency Involvement

There is no OCR headquarters staff assigned as a technical assistance liaison with the regional offices or the operating divisions (OPDIVS). OCR does not routinely train OPDIV staff at the headquarters level.⁷⁰⁶ However, OCR has provided technical assistance and training to OPDIVs when requested. For example, OCR is currently working with the Health Care Financing Administration (HCFA) to provide training on title VI, the Americans with Disabilities Act, and section 504 of the Rehabilitation Act to all HCFA employees.⁷⁰⁷ In addition, OCR and OGC worked with the Administration for Children and Families to provide training and technical assistance on title VI and other civil rights issues.⁷⁰⁸

⁷⁰² *Ibid.*, tab 14, Hispanic Outreach Log FY '98 and Memorandum, Significant Activities Report, June 1998.

⁷⁰³ OCR Region III, Response to Information Request, tab 14, Hispanic Outreach Log FY '98 and Memorandum, Significant Activities Report, June 1998.

⁷⁰⁴ OCR Region IX, Response to Information Request, p. 4.

⁷⁰⁵ *Ibid.*

⁷⁰⁶ *Ibid.*, pp. 2, 10 (statements of Shepperd).

⁷⁰⁷ *Ibid.*, p. 17 (statement of Copeland). OPDIVS are discussed in more detail in chap. 5.

⁷⁰⁸ *Ibid.*, pp. 15–16 (statement of Copeland).

OCR regional offices are required to conduct education and outreach activities, which includes technical assistance activities for and with OPDIVS.⁷⁰⁹ The regional offices submit activity reports on technical assistance and outreach activities to OCR headquarters. However, there is no specific contact person.⁷¹⁰ The interaction between OPDIVS and the regional offices varies from having continuous or consistent communication, to OCR providing informal guidance on particular civil rights issues,⁷¹¹ to participating in jointly organized seminars and conferences. Since OCR has limited resources for outreach, some of the regional offices are skillful at "piggy-backing" on what the OPDIVS are doing in technical assistance and outreach. They use the opportunity to make certain that civil rights information is included at cosponsored conferences and programs.⁷¹² For example, in 1998 one regional office cosponsored a conference with HCFA for culturally diverse populations. Over 400 persons attended and approximately 100 presentations were made from persons in the field of cultural competence in health care.⁷¹³ Similarly, regional offices have participated in joint customer outreach meetings with OPDIVS to conduct briefings on various HHS initiatives and programs that are targeted primarily to HHS customers, including State and local agencies, beneficiaries, advocacy groups, and universities.⁷¹⁴ For example, Region IX has

⁷⁰⁹ OCR FY 1998 AOP guidance, Director's National Priorities, pp. 1–7. *See also* OCR Region III, Response to Information Request, "FY 1999 Annual Operating Plan, Director's National Priorities," tab A.

⁷¹⁰ OPO interview, p. 22 (statement of Nelson).

⁷¹¹ *See* OCR Region V, Response to Information Request, p. 11.

⁷¹² OPO interview, p. 22 (statement of Mackey); OCR Region III, Response to Information Request, p. 3.

⁷¹³ *See* Michael R. Carter, regional manager, Region II, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, January 1999 (re: Response to Information Request), index of attached documents, # 7, National Conference on Quality Health Care for Culturally Diverse Populations.

⁷¹⁴ In Region I, OCR staff conducted joint meetings with OPDIVS on such initiatives as HHS' Asian and Pacific Islander initiative to community leaders (LEP), the Multiethnic Placement Act, and the Children's Health Insurance Program. *See* OCR Region I, Response to Information Request, p. 4. In Region III, for example, joint activities with the OPDIVS focused on a number of departmental priority areas, including welfare reform, foster care and adoption, and CHIP. OCR Region III, Response to Information Re-

conducted joint outreach activities with at least one OPDIV in sponsoring a series of HHS regional forums on HIV in women and ethnic minorities, the Children's Health Insurance Program (CHIP), an Asian and Pacific Islander Initiative, and other HHS initiatives.⁷¹⁵

State Recipients of Block Grant Funds

Although HHS has not systematically monitored States' title VI compliance, it has taken steps that may lead to improved monitoring. During FY 1995 and FY 1996, OCR Region VII partnered with the Missouri Department of Health to provide title VI training to the State's county health officials.⁷¹⁶ In June 1998, Region II staff explained OCR's LEP memorandum and provided an update on all Federal statutes enforced by OCR to the State of New York Department of Health's Hospital and Primary Care Services.⁷¹⁷ During FY 1998, Region VII staff held a briefing on LEP issues and distributed training materials to inform State agency staff that denying LEP minorities equal opportunity to benefit from services provided by HHS recipients is a violation of title VI.⁷¹⁸

Similarly, in mid-1998, Region VIII held a briefing in Colorado on OCR's policy regarding LEP discrimination.⁷¹⁹ Region X met with State agencies in response to numerous telephone calls complaining about the State of Washington's cutbacks in funding for interpreter services for medicaid clients.⁷²⁰ The complainants argued that the cuts reflected the State agency's diminishing commitment to ensuring equal access to the multitude of services it provides.⁷²¹ OCR met with and entered into partnerships with key

State and local officials to ensure that LEP and other minority clients would continue to receive equal services, and intended to meet regularly with State and local agency officials in Washington to find solutions to problems as they arise.⁷²²

In addition, State officials have approached regional OCR offices for technical assistance on OCR policies.⁷²³ This was particularly the case when States received OCR's policy guidance on the Multiethnic Placement Act.⁷²⁴ For example, for FY 1998, Region I planned a technical assistance session on the interethnic adoption provisions of the Small Business Job Protection Act of 1996 to various State agencies in its region.⁷²⁵ OCR planned to: (a) provide States with the MEPA guidance memorandum and offer subsequent technical assistance, (b) coordinate with ACF to conduct a presentation with State agency staff, (c) conduct a technical assistance meeting with State officials, (d) determine the particular changes that are required in State policies, procedures, and statutes, and (e) establish a training schedule with State agency staff.⁷²⁶

Nonetheless, several State agencies indicated that they had not received technical assistance or training from OCR. For example, the administrator of the Health Division of the Nevada Department of Human Resources stated that her agency had not received technical assistance or guidance from OCR and further noted that "HHS relies on the state's assurances and the state's monitoring of block grant and contractor compliance [to ensure subrecipients' compliance with civil rights statutes]."⁷²⁷

Future of OCR's Technical Assistance, Outreach, and Education Program

OCR has yet to recognize that although implementing the fundamental civil rights compliance tools of education, outreach, training, and

quest, p. 3; tab 16. Alfred J. Sanchez, regional manager, Region V, OCR, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 15, 1999 (re: request for information), p. 8 (hereafter cited as OCR Region V, Response to Information Request).

⁷¹⁵ OCR Region IX, Response to Information Request, p. 4.

⁷¹⁶ OCR Region VII, Response to Information Request, p. 8.

⁷¹⁷ Michael Carter, regional manager, Region II, OCR, HHS, memorandum to Ronald Copeland, associate deputy director, Office of Program Operations, July 7, 1998 (re: Monthly Significant Activities Report (SAR) for the Month of June 1998), p. 1.

⁷¹⁸ HHS, OCR, Region VII, FY 1998 Annual Operating Plan.

⁷¹⁹ HHS, OCR, Region VIII, FY 1998 Annual Operating Plan.

⁷²⁰ HHS, OCR, Region X, FY 1998 Annual Operating Plan.

⁷²¹ Ibid.

⁷²² Ibid.

⁷²³ OPO interview, pp. 43-44 (statement of Mackey)

⁷²⁴ Ibid., p. 44 (statement of Mackey).

⁷²⁵ OCR Region I, FY 1998 AOP.

⁷²⁶ Ibid.

⁷²⁷ Yvonne Salva, administrator, Health Division, Department of Human Resources, State of Nevada, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: information for health care report), enclosure, p. 6.

technical assistance may seem prohibitively costly for an already underfunded civil rights enforcement program, the benefits of these activities may easily outweigh the costs. For instance, by providing increased funding for community outreach and education, HHS could increase the number of valid title VI complaints, while reducing the number of faulty complaints. More importantly, by involving the affected communities in the enforcement of their own rights, HHS could simultaneously empower large numbers of people, while improving its own effectiveness.

Other Federal civil rights enforcement agencies have relied far more on "high-tech" and other resources to develop sophisticated methods of disseminating such information to the public. For example, the Commission found that in educating the public about compliance with the Americans with Disabilities Act (ADA), both the U.S. Department of Justice and the U.S. Equal Employment Opportunity Commission utilized various "high-tech" and other vehicles to disseminate information about the law.⁷²⁸ In addition to a telephone hotline and the Internet, the Commission found that the Department of Justice's Disability Rights Section uses such means as contacting libraries and disability advocacy groups, issuing public service announcements, and providing technical assistance to private and public officials to disseminate information.⁷²⁹ OCR has not used such tools.

Many of the regional managers who were interviewed thought that their offices were not "high tech" in their operations and abilities to gather, create, or disseminate information.⁷³⁰ Nonetheless, OCR must make better use of available technologies to upgrade its capabilities for disseminating technical assistance informa-

tion. Currently, electronic availability of OCR's documents and materials appears limited to its Web site on the Internet. OCR has not provided key information, such as its title VI and Hill-Burton fact sheets and other technical assistance materials it has developed, to electronic research systems and databases available to public and university libraries, nursing homes, hospitals, and other research and community resources. One example of the kind of "high-tech" vehicle that OCR might use is MEDLINE^{plus}, a medical resource for the public that includes MEDLINE—the world's largest medical database of peer-reviewed information.⁷³¹ MEDLINE was launched by NIH's National Library of Medicine. It has created Internet links with self-help groups, consumer organizations, clearinghouses and libraries, health-related organizations, and clinical trials to disseminate information and increase public awareness of medical information.⁷³² As part of a pilot project, the National Library of Medicine also plans to work with public libraries nationwide to increase public awareness of and access to health information.⁷³³

Another gauge of the inadequacy of OCR's efforts in this area is a comparison with the efforts of its counterpart civil rights enforcement offices and with outside agencies. To explain, in addition to the Civil Rights Review Team's recommendations for external outreach, OCR has received suggestions for improving its outreach efforts from at least one other departmental report. In 1992 HHS' Office of the Inspector General (OIG) recommended that one of the efforts OCR should use to strengthen Hill-Burton enforcement efforts is to determine whether technical assistance guides and methods developed in individual regions could be shared nationally.⁷³⁴ Specifically, the OIG report stated that OCR "should explore methods that would enable

⁷²⁸ See USCCR, *Helping State and Local Governments Comply with the ADA: An Assessment of How the United States Department of Justice Is Enforcing Title II, Subpart A, of the Americans with Disabilities Act*, September 1998, pp. 116–31 (hereafter cited as USCCR, *An Assessment of DOJ's Enforcement of the ADA*); USCCR, *Helping Employers Comply with the ADA: An Assessment of How the United States Equal Employment Opportunity Commission Is Enforcing Title I of the Americans with Disabilities Act*, September 1998, pp. 220–41.

⁷²⁹ USCCR, *An Assessment of DOJ's Enforcement of the ADA*, pp. 123–24.

⁷³⁰ See Carter interview, p. 7; Halverson interview, p. 8. See also chap. 3.

⁷³¹ The National Library of Medicine is the world's largest medical library that provides timely and critical medical health information. HHS, National Institutes of Health, National Library of Medicine, NIH news release, Oct. 22, 1998, p. 1 (hereafter cited as NIH news release).

⁷³² NIH news release, p. 1.

⁷³³ *Ibid.*

⁷³⁴ See HHS/OIG, *Oversight of the Hill-Burton Program*, pp. ii.

them to share the expertise developed in one regional office with other regional office staff.”⁷³⁵

At least two regions have used databases to distribute their information to the general public. With support from the Health Care Financing Administration, Region II posted information, including abstracts, resource material, and biographical descriptions of presenters at a conference on the Diversity Rx Web site.⁷³⁶ Another region has developed a database for some of its contractors. Thus, it is highly feasible that other regional offices, and OCR headquarters in particular, could develop its own and use various databases that can include all of the statutes it enforces, as well as general civil rights in health care information. This information could be channeled through organizations, public and private facilities such as hospitals and libraries, and universities. If OCR were to make technical assistance information on its civil rights enforcement activities available via computer databases, they could become very effective vehicles for dissemination, reaching a broad range of stakeholders such as recipients, beneficiaries, and government officials, as well as the general public.

Some regions have devised unique technical assistance programs. For example, in 1996 Region V began to sponsor civil rights seminars through a community college to health care professionals. The seminars covered all of the jurisdictions with case examples.⁷³⁷ By FY 1998, the project expanded to four sites. In FY 1996, the same regional office developed a videotape on MEPA that was produced in conjunction with the Illinois Department of Children and Family Services and a local university. The videotape was used by the Illinois department to train caseworkers and staff who work in private adoption agencies. The project was implemented

without the use of OCR travel funds.⁷³⁸ Another regional office has a video that it uses to provide information on LEP issues.⁷³⁹ Other regional staff have made appearances on radio and television programs.⁷⁴⁰ Several regions have provided the standard fact sheets in numerous languages.⁷⁴¹ Although a few regions have implemented innovated techniques to providing technical assistance, outreach, and education, there have been few new methods employed by the regions.

Efforts to strengthen OCR’s technical assistance and outreach and education program might include a stronger component for addressing racial or ethnic prejudice among medical professionals. There is evidence that this may be a problem OCR needs to confront. It may also be a problem whose solution is particularly well-suited to outreach and education efforts. For example, a recently published article reported research findings that showed doctors are far less likely to recommend rigorous and more sophisticated cardiac tests for black people and women than for white men with identical complaints of chest pains.⁷⁴² The widely publicized article described a study in which researchers found that doctors prescribed the cardiac catheterization only 60 percent as often for black males and women and 40 percent as often for black women as compared to white men.⁷⁴³ The authors of the study could not draw any inferences of overt racism or sex bias from their findings.⁷⁴⁴ However, they suggested instead that the problem may be the result of “subconscious perceptions rather deliberate actions.”⁷⁴⁵

Outreach and education may be particularly well-suited to address this problem because it may derive at least in part from a lack of awareness and understanding of minority health con-

⁷³⁵ Ibid., p. 9. One of the findings in the report was that individual staff members and regions developed their own techniques to facilitate Hill-Burton compliance reviews and complaint investigations. In Philadelphia, OIG found a system to coordinate complaints received by HCFA and OCR. In the San Francisco regional office, OIG found a regional training manual. However, these guides and methodologies were not shared with other regional offices and, in most cases, confined to the region that developed them. Ibid., p. 7.

⁷³⁶ OCR Region II, Response to Information Request, index of attached documents, # 7, National Conference on Quality Health Care for Culturally Diverse Populations.

⁷³⁷ OCR Region V, Response to Information Request, p. 7.

⁷³⁸ Ibid.

⁷³⁹ OCR Region VII EOS interview, p. 7.

⁷⁴⁰ Ibid.; OCR Region IX EOS interview, p. 6; Chang interview, p. 9.

⁷⁴¹ OCR Region VI EOS interview, p. 3; OCR Region IX EOS interview, p. 6.

⁷⁴² See Kevin A. Shulman and others, “The Effect of Race and Sex on Physicians’ Recommendations,” pp. 618–26.

⁷⁴³ Ibid., pp. 618–19.

⁷⁴⁴ Goldstein, “GU Study Finds Disparity in Heart Care,” pp. A–1, A–13.

⁷⁴⁵ Ibid., p. A–13.

cerns among medical students. In order to address this problem, a professor of ethnic studies at the University of California has suggested "[c]ourses need to be established in medical schools to make doctors multi-culturally literate. To graduate from Berkeley, you must understand the diversity of America and how health varies within minorities."⁷⁴⁶

Along these lines, one means for OCR to focus more closely on addressing discrimination by medical practitioners and other professionals

may be targeting the 130 medical schools in the U.S. for outreach and education and encouraging the promotion of race and gender awareness programs. Today, fewer than 15 medical schools in the United States have any type of race or gender awareness program.⁷⁴⁷ Yet if OCR could make it a goal to ensure that all medical schools have such a program, it may be able to have a strong influence on the way doctors relate to and view their patients.

⁷⁴⁶ Jay Greene, "Medical educators must increase diversity in medicine by recruiting strong minority students," *American Medical News*, vol. 41, no. 46 (Dec. 14, 1998).

⁷⁴⁷ Goldstein, "GU Study Finds Disparity in Heart Care," p. A-13.

Chapter 5

The Role of HHS Operating Divisions in Supporting Civil Rights Enforcement Efforts

"[N]one of the operating divisions requires applicants to submit sufficient information in their applications to determine their title VI compliance status, and none conducts title VI preaward reviews of their applicants."¹

"[S]pecific procedures delineating the relative responsibilities of OCR and the operating divisions will be necessary to ensure effective title VI enforcement throughout HHS."²

The Department of Health and Human Services (HHS) encompasses a number of smaller agencies, known as operating divisions (OPDIVS). Because they are the primary source of Federal health care funding, these agencies can play a vital role in supporting OCR's efforts to ensure civil rights compliance. These agencies were formerly part of the U.S. Public Health Service and were designated as OPDIVS reporting directly to the HHS Secretary under a 1995 Reorganization Plan.³ Some OPDIVS have missions that are more obviously related to civil rights than others:

- The *National Institutes of Health* (NIH) conducts medical and scientific research that helps extend health and reduce burdens resulting from disease and disability.⁴

- The *Centers for Disease Control and Prevention* (CDC) promotes the health and quality of life by preventing and controlling disease, injury, and disability.⁵
- The *Food and Drug Administration* (FDA) promotes public health by reviewing clinical research and taking appropriate action on marketing regulated products; and ensures that foods are safe, wholesome and sanitary and that drugs and medical devices are safe and effective.⁶
- The *Substance Abuse and Mental Health Services Administration* (SAMHSA) promotes the prevention and treatment of addictive and mental disorders generally, but also among minorities who disproportionately suffer the effects of substance abuse and mental illness.⁷
- The *Health Care Financing Administration* (HCFA) administers medicare and medicaid, programs that provide health insurance to over 74 million Americans,⁸ large portions of

¹ U.S. Commission on Civil Rights (USCCR), *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, June 1996, p. 221 (hereafter cited as USCCR, *Federal Title VI Enforcement*) (citations omitted).

² *Ibid.*, pp. 221–22.

³ 60 Fed. Reg. 56,605 (1995).

⁴ U.S. Department of Health and Human Services (HHS), *National Institutes of Health, Organization Handbook, Manual 1123*, June 1998, p. 13. See Ruth L. Kirschstein, M.D., deputy director, National Institutes of Health, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 22, 1999 (re: request for information), tab 1 (hereafter cited as NIH, Response to Information Request).

⁵ HHS, Centers for Disease Control and Prevention, *Fact Book, FY 1998*, p. 2 (hereafter cited as CDC, *Fact Book*). See Candice Nowicki-Lehnherr, deputy director, Executive Secretariat, Centers for Disease Control and Prevention, HHS, letter to Eileen Rudert, Office of Civil Rights Evaluation, USCCR, no date (sent Federal Express, Mar. 24, 1999) (re: request for information), tab B (hereafter cited as CDC, Response to Information Request).

⁶ HHS, Food and Drug Administration, "[Staff Manual] Guide—1110.1, Organization and Delegations," "Mission," p. 1. See Rosamelia T. Lecea, director, Office of Equal Employment and Civil Rights, Food and Drug Administration, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: request for information), tab 3 (hereafter cited as FDA, Response to Information Request).

⁷ HHS, Substance Abuse and Mental Health Services Administration, "Mission Statement," and "Office of the Administrator, Office of Minority Health," accessed at <<http://www.samhsa.gov/organ/index.htm>>, pp. 1, 3.

⁸ HHS, Health Care Financing Administration, "Welcome to HCFA," accessed at <<http://www.hcfa.gov>>, p. 1.

whom are African American or members of other minority groups.⁹

- The *Health Resources and Services Administration* (HRSA) promotes quality health care to underserved, vulnerable and special-need populations including racial/ethnic minorities.¹⁰
- The *Agency for Health Care Policy and Research* (AHCPR) supports research designed to improve the quality of health care, reduce its cost, and broaden access to essential services generally.¹¹
- The *Administration for Children and Families* (ACF) operates programs that promote the economic and social well-being of families, children, individuals, and communities including, for example, low-income assistance programs, foster care, and adoption programs.¹²
- The *Agency for Toxic Substances and Disease Registry* (ATSDR) aims to prevent exposure and adverse human health effects of exposure to hazardous substances from waste sites, unplanned releases, and other environmental sources of pollution.¹³
- The *Indian Health Service* (IHS) tries to assure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people.¹⁴
- The *Administration on Aging* (AoA) helps the Nation prepare for the unprecedented growth of its older population in upcoming years and works with States, senior centers, and local

service providers to assist older persons in remaining independent in their homes and communities.¹⁵

The 1998 *Catalog of Federal Domestic Assistance* listed nearly 1,000 programs that the HHS OPDIVS administered.¹⁶ These programs provide a variety of health-related activities and services. Some of the programs that HHS assists financially are best characterized by the types of activities they fund, for example, research grants, training grants, and service grants.¹⁷ Others may be more distinctive in how they are administered, for example, block grants and cooperative agreements.¹⁸ HHS also funds entities through health insurance reimbursement arrangements, such as medicare or medicaid.¹⁹ The kinds of recipients also vary. The recipients of HHS financial assistance represent a broad range of entities and individuals, including State and local governments; Indian tribes and organizations; public and private for-profit and not-for-profit institutions; and students in the health professions, faculty, and health care practitioners.²⁰ Some recipients receive HHS funding through a number of different sources.²¹

The Secretary's delegation of authority makes clear that the HHS Office for Civil Rights (OCR), not the OPDIVS, has sole responsibility for extramural civil rights enforcement, including processing and investigating complaints of discrimination, as well as conducting compliance

⁹ HHS, Health Care Financing Administration, "1997 HCFA Statistics," tables 3 and 13.

¹⁰ HHS, Health Resources and Services Administration, "Office of the Administrator," accessed at <<http://www.hrsa.dhhs.gov/oa.html>>, p. 1 (hereafter cited as HRSA Web site).

¹¹ HHS, Agency for Health Care Policy and Research "AHCPR Overview," accessed at <<http://www.ahcpr.gov/about/overview.htm>>, p. 1.

¹² HHS, Administration for Children and Families, "ACF Press Room," accessed at <<http://www.acf.dhhs.gov/programs/opa/facts/major.htm>>, Feb. 25, 1999.

¹³ HHS, Agency for Toxic Substances and Disease Registry, "About ATSDR," accessed at <<http://www.atsdr.cdc.gov/atsdrhome.html#A1>>.

¹⁴ HHS, Indian Health Service, Mission Statement. See Michael H. Trujillo, M.D., M.P.H., M.S., assistant surgeon general, director, Indian Health Services, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Apr. 29, 1999, tab 3 (hereafter cited as IHS, Response to Information Request).

¹⁵ HHS, Administration on Aging, "U.S. Administration on Aging: Accomplishments 1993-1996," accessed at <<http://www.aoa.dhhs.gov/aoa/pages/accomp96.html>>.

¹⁶ See Executive Office of the President, Office of Management and Budget, *1998 Catalog of Federal Domestic Assistance* (Washington, DC: General Services Administration, 1998), Applicant Index, HHS, pp. AE1-21-28 (hereafter cited as *1998 CFDA*).

¹⁷ *Ibid.*, pp. 965, 1053, 1079, 1324.

¹⁸ *Ibid.*, pp. 961, 1167.

¹⁹ *Ibid.*, pp. 1203-05.

²⁰ *Ibid.*, pp. 1033, 1053, 1073.

²¹ Caroline Chang, regional manager, Region I, Office for Civil Rights (OCR), HHS, telephone interview, Feb. 17, 1999, p. 2; Arnold Loperena, Patricia Holub, and Victor Hidalgo, equal opportunity specialists, Region II, OCR, HHS, telephone interview, Feb. 3, 1999, p. 5; Andrea Oliver, Jean Lovato, and Doris Genko, equal opportunity specialists, Region VIII, OCR, HHS, telephone interview, Feb. 9, 1999, p. 9.

Table 5.1
Operating Divisions' Offices Concerned with Civil Rights

<u>Name of civil rights office or staff</u>	<u>Operating divisions with:</u>	
	<u>Office</u>	<u>Staff</u>
Exclusively extramural civil rights: "Civil Rights"	none	
Equal opportunity and civil rights combined: "Equal Opportunity and Civil Rights"	HCFA, ¹ HRSA ¹	
"Equal Employment Opportunity and Civil Rights"	SAMSHA ¹	IHS, ² ACF ²
"Equal Employment and Civil Rights"	FDA ¹	
Equal opportunity only: "Equal Opportunity"	NIH ¹	
"Equal Employment Opportunity"	CDC ¹	AHCPR ²
None	AoA, ² ASTDR ²	

SOURCES:

¹ 1998 or 1999 organizational charts submitted in response to Dec. 2, 1998, document request.

² *Federal Yellow Book* (Washington, DC: Leadership Directories, Inc., 1999).

reviews of recipients of Federal assistance.²² However, because of the many grant, contract, and assistance programs the OPDIVS administer, these agencies can influence the effectiveness of OCR's civil rights enforcement efforts. In particular, the OPDIVS can affect civil rights enforcement by referring complaints to OCR, ensuring that HHS funding recipients are in compliance with civil rights laws before approval of grants and contracts, and making policy and program decisions, such as how funds will be distributed and what kind of data collection will be required of recipients.

The way in which OCR and the OPDIVS delineate their authority and roles is critical to how well the OPDIVS can support OCR's efforts to implement and enforce civil rights laws. The organizational structure, resources, and staff of the OPDIVS, the familiarity of OPDIV personnel with civil rights requirements of funding recipients, and the understanding among the OPDIVS

of HHS civil rights regulations and guidance are crucial to complementing OCR's civil rights enforcement efforts.

The OPDIVS' headquarters and regional structure affects the quality of any extramural civil rights activities HHS and OCR may call on them to perform. These structures also affect the interaction between each OPDIV and OCR by helping to determine the extent, if any, to which a particular OPDIV can assist OCR in carrying out its civil rights enforcement efforts.

Because the Secretary has delegated sole authority for civil rights enforcement to OCR, none of the OPDIVS has an office devoted exclusively to extramural civil rights matters, such as enforcement of title VI, title IX, the Hill-Burton Act, and the nondiscrimination provisions contained in block grant statutes created with the Omnibus Budget Reconciliation Act of 1981.²³

²³ OCR is responsible for enforcing title VI of the Civil Rights Act of 1964, Pub. L. No. 88-352, title VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d-2000d-7 (1994)); title IX of the Education Amendments of 1972, Pub. L. No. 92-318, title IX, 86 Stat. 373 (codified as amended at 20 U.S.C. §§ 1681-1688 (1994)); the Hill-Burton Act, Pub. L. No. 79-725, 60 Stat. 1040 (1946) (codified as amended at 42 U.S.C. §§ 291-291-o (1994)) (enacting title VI of the Public Health Service Act); Pub. L. No. 93-641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q-300t (1994)) (enacting title XVI of the Public Health Service Act); and nondiscrimination provisions of block grant statutes, Pub. L. No. 97-35, sec. 901, §§ 1908, 1918, sec. 2192(a), § 708, § 2606, § 677, 95

²² 47 Fed. Reg. 20,032-35 (1982). For purposes of this discussion, the term "extramural civil rights" refers only to enforcement of title VI, title IX, Hill-Burton, and the nondiscrimination provisions in block grant statutes. The term "internal civil rights" refers to such activities as reviewing affirmative action plans, personnel policies, recruitment procedures, and staffing activities; and handling and resolving internal employment complaints (i.e., processing title VII claims of employment discrimination by OPDIV employees).

Rather, the OPDIVS have functions concerning equal employment opportunity of their internal work forces.²⁴ The lack of a designated office to focus extramural civil rights responsibilities appears to have resulted in scattered and sometimes disorganized efforts to address civil rights matters.

Several OPDIVS do not appear even to have staff designated to address internal civil rights matters, such as equal employment within the agency. For example, according to the *Federal Yellow Book*,²⁵ neither the Administration on Aging nor the Agency for Toxic Substances and Disease Registry has any internal equal employment opportunity office or staff person meriting mention.²⁶ Two OPDIVS, CDC and NIH, have offices that appear from their titles to address only internal equal employment opportunity matters.²⁷ The Agency for Health Care Pol-

Stat. 357, 542, 551, 825, 900, 516 (codified as amended at 42 U.S.C. §§ 300x-7(a)(1)-(2); 300w-7(a)(1)-(2); 708 (a)(1)-(2); 8625(a); 9906(a) (1994 & Supp. II 1996)).

²⁴ See table 5.1 (showing the names of OPDIV offices or staff (when there is not an office) concerned with civil rights matters). OCR staff confirmed the lack of OPDIV offices devoted exclusively to extramural civil rights. See Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy director, Valita Shepperd, deputy director, Program Development and Training Division; Ronald Copeland, associate deputy director; Johnny Nelson, deputy director, Voluntary Compliance and Outreach Division; Toni Baker, director, Investigations Division; Office of Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13 and 18, 1998, pp. 13-14 (statement of Nelson) (hereafter cited as OPO interview); Marcella Haynes, director, Policy and Special Projects Staff, and Kathleen O'Brien, special assistant, OCR, HHS, interview in Washington, DC, Nov. 16, 1998, p. 34 (statement of Haynes) (hereafter cited as PSPS interview).

²⁵ For items in the chart referring to the *Federal Yellow Book*, the Commission did not receive detailed organizational charts.

²⁶ *Federal Yellow Book* (Washington, DC: Leadership Directories, Inc., 1999), cover and pp. II-252, II-256-57 (hereafter cited as *Federal Yellow Book*).

²⁷ The CDC has an Office of Equal Employment Opportunity, the mission of which is to "promote diversity and equal employment opportunity through . . . training, prompt processing of complaints, effective special emphasis initiatives, affirmative employment, and alternative dispute resolution. . . ." CDC, *Fact Book*, p. 95.

NIH's Office of Equal Opportunity may have some extramural activities among internal equal opportunity functions. For example, it "reviews efforts and makes recommendations to implement the NIH civil rights program as it relates to research contractors and grantees. . ."; "maintains liaison with NIH components that administer programs to increase the participation of minorities in biomedical research"; and

icy and Research has only an assistant administrator for equal employment opportunity, not an office.²⁸ Finally, HCFA, HRSA, FDA, and SAMHSA have offices combining equal employment opportunity with broader civil rights functions, while the Indian Health Service and the Administration for Children and Families each have a "staff," rather than an office, combining these functions.²⁹

In trying to respond to the Commission's request for information and documents concerning extramural civil rights activities, two of the OPDIVS stated that assembling a response was difficult because they did not have an office of civil rights and information had to be collected from various offices throughout the agency.³⁰

"performs studies and analyses necessary to support the equal employment opportunity and civil rights functions" (emphasis added). "NIH Organization and Functions, Office of the Director (HNA), Office of Equal Opportunity (HNAD)." See NIH, Response to Information Request, tab 2. The NIH's Office of Equal Opportunity's liaison activities include both internal and external activities. Ruth L. Kirschstein, deputy director, Public Health Service, National Institutes of Health, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 2, 1999 (re: health care report), attachment, p. 4 (hereafter cited as Kirschstein letter).

²⁸ See table 5.1. AHCPR's assistant administrator for Equal Opportunity is located in the Office of the Administrator. *Federal Yellow Book*, p. II-247. No office was designated in the organizational chart AHCPR submitted to the Commission. See John M. Eisenberg, M.D., administrator, Agency for Health Care Policy and Research, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 25, 1999 (re: request for information), tab B (hereafter cited as AHCPR, Response to Information Request).

²⁹ See table 5.1. Note that IHS has an "Equal Employment Opportunity and Civil Rights Staff" headed by a director. See HHS, Public Health Service, Indian Health Service, Organizational Chart, Mar. 12, 1999. See IHS, Response to Information Request, tab 1. According to the *Yellow Book*, it is an "Equal Employment Opportunity Staff." *Federal Yellow Book*, p. II-275.

³⁰ Thena Durham, director of the Executive Secretariat, Centers for Disease Control and Prevention, HHS, telephone conversation with Eileen Rudert, Office of Civil Rights Evaluation, USCCR, Mar. 5, 1999; Candice Nowicki, deputy director, Executive Secretariat, Centers for Disease Control and Prevention, HHS, telephone conversation with Eileen Rudert, Office of Civil Rights Evaluation, USCCR, Mar. 22, 1999; Cecilia Heftel, EEO director, Indian Health Service, HHS, telephone conversation with Eileen Rudert, Office of Civil Rights Evaluation, USCCR, Mar. 1, 1999 (hereafter cited as Heftel, Mar. 1, 1999, conversation). The Commission's requests for information and documents were dated Dec. 2, 1998, and the Commission finally received responses from CDC and IHS on Mar. 25, and Apr. 29, 1999, respec-

Among the four offices that do have broader civil rights functions, internal equal opportunity functions dominated the workload. Few extramural civil rights functions were specified in the office functions, and few staff were assigned to carry out these functions.

Civil Rights Offices within OPDIVS

Substance Abuse and Mental Health Services Administration

The Substance Abuse and Mental Health Services Administration (SAMHSA)'s Office of Equal Employment Opportunity and Civil Rights (EEOCR) performs the typical equal opportunity functions. It processes complaints of employment discrimination, develops the agency's special emphasis and affirmative employment programs, and plans and develops internal civil rights compliance policy.³¹ It serves as the "internal advocate" for civil rights and related principles; and assesses the agency's compliance with applicable civil rights statutes, executive orders, regulations, policies, and programs.³²

According to SAMHSA, the agency's EEO office had always performed some civil rights activities on an informal level since the agency was established in October 1992.³³ To expand and elevate the significance of these activities, formal civil rights responsibilities were added to the office in September 1998³⁴ and the office now

tively. See CDC, Response to Information Request; IHS, Response to Information Request.

³¹ HHS, Substance Abuse and Mental Health Services Administration, Mission and Functional Statements, October 1998, p. 9, "Office of the Administrator, Office of Equal Employment Opportunity and Civil Rights" (hereafter cited as SAMHSA, Mission and Functional Statements). See Nelba Chavez, administrator, Substance Abuse and Mental Health Services Administration, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 13, 1999 (re: request for information), tab 3 (hereafter cited as SAMHSA, Response to Information Request).

³² SAMHSA, Mission and Functional Statements, p. 9.

³³ Nelba Chavez, administrator, Substance Abuse and Mental Health Services Administration, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, July 8, 1999, p. 3 (hereafter cited as Chavez letter).

³⁴ Ibid.

addresses extramural civil rights functions.³⁵ OCR staff met with SAMHSA staff to familiarize them with civil rights matters apart from equal opportunity issues and anticipated that because of the newly created office, SAMHSA would no longer handle its civil rights matters as day-to-day actions or special assignments.³⁶ As of June 1999, there was no formal memorandum of understanding (MOU) or other agreement between OCR and SAMHSA defining exactly what extramural civil rights activities SAMHSA's EEOCR office will perform or who will provide necessary training to SAMHSA staff to carry out these functions.³⁷ However, according to SAMHSA, the directors of OCR and EEOCR were scheduled to meet so that a program decision could be made regarding SAMHSA's role in civil rights implementation, as SAMHSA expected to play a role in the administration of this program.³⁸

Food and Drug Administration

The Food and Drug Administration (FDA)'s Office of Equal Employment and Civil Rights' (OEECR) does not appear to have extramural civil rights responsibilities. The office has two branches: the Affirmative Action and Complaints branch and the Special Emphasis and Initiatives branch. The Affirmative Action and Complaints branch focuses on internal civil rights matters, such as reviewing affirmative action plans, personnel policies, recruitment procedures, and staffing activities; and handling and resolving internal employment complaints.³⁹ The Special Emphasis and Initiatives branch has many functions concerning internal employ-

³⁵ This office was included only in SAMHSA's 1998 organization chart. See SAMHSA, Response to Information Request, tab 1, organizational charts; OPO interview, pp. 13-14 (statement of Nelson).

³⁶ OPO interview, pp. 13-14 (statement of Nelson).

³⁷ Despite the lack of an MOU with OCR, SAMHSA's EEOCR has actively sought a greater role in the area of civil rights enforcement. According to SAMHSA, the EEOCR's director initiated a meeting with the acting OCR director in October 1998 for the purpose of communicating the office's interest in such a role. See Chavez letter, p. 4.

³⁸ See *ibid.*

³⁹ HHS, Food and Drug Administration, "[Staff Manual] Guide—1111.1, Organization and Delegations," transmittal no. 98-03 (Nov. 12, 1998), pp. 2-4 (hereafter cited as FDA Organization). See FDA, Response to Information Request, tab 3.

ment. In addition, it advises FDA components regarding nondiscriminatory procurement and material management; establishes relationships with minority-oriented professional organizations and health-related higher education institutions; and participates in the Historically Black Colleges and Universities (HBCU) Initiative.⁴⁰ But, although the HBCU initiative is clearly extramural, neither of the branch offices has responsibilities that mention grantees or other funding recipients. In most functions, the vague language of "civil rights activities" or "matters" has merely been added to equal employment opportunity (EEO) responsibilities.⁴¹

FDA OEECR staff emphasized that the office focused on internal equal employment opportunity matters rather than extramural civil rights.⁴² Although staff viewed every civil rights issue within FDA as under the office's purview, no extramural civil rights enforcement role had been delegated to the office. In 1999 the office had 18 staff, but less than 1 full-time employee was devoted to extramural civil rights matters.⁴³

Health Resources and Services Administration

The functions of the Health Resources and Services Administration (HRSA)'s Office of Equal Opportunity and Civil Rights (OEOCR) include not only internal employment matters (e.g., administering affirmative action programs, managing the civil service complaints system) but also developing and directing implementation of title VI of the Civil Rights Act as it applies to recipients of HRSA funds.⁴⁴ In keeping with this function, the OEOCR staff conducts site visits throughout the year to monitor civil rights compliance in federally conducted programs or assisted organizations.⁴⁵ However, ap-

parently there are few resources devoted to HRSA's extramural civil rights activities. In 1999 HRSA's OEOCR had a staff of 14, including 5 EEO officers and a civil rights officer.⁴⁶ Only one of these employees was engaged in extramural civil rights activities. The civil rights officer conducted all the site visits, attempting to schedule two per month.⁴⁷

Health Care Financing Administration

The OPDIV with the most interaction with OCR is the Health Care Financing Administration (HCFA), and OCR has delegated more authority for civil rights enforcement activities to HCFA than any other OPDIV. OCR entered into a formal MOU with HCFA in 1979.⁴⁸ However, the extent to which HCFA performs extramural civil rights functions remains unclear. On the surface, the functions and activities of HCFA's Office of Equal Opportunity and Civil Rights (OEOCR) appear to revolve around equal opportunity and internal civil rights activities rather than extramural civil rights issues with respect to HCFA federally assisted programs or recipients. OEOCR functions include:

- Providing leadership and advice on issues related to diversity and civil rights.
- Developing, implementing, and managing affirmative employment programs.
- Developing EEO and civil rights compliance policy.
- Identifying policy and operational issues and proposing solutions for resolving such issues within the agency.
- Receiving and evaluating complaints for procedural sufficiency, and resolving such complaints.
- Promoting the representation of women and minority groups through outreach activities.

⁴⁰ FDA Organization, pp. 2-4.

⁴¹ Ibid.

⁴² Rosamelia T. Lecea, director, and Rosa Morales, deputy director, Office of Equal Employment and Civil Rights, Food and Drug Administration, HHS, telephone interview, Mar. 8, 1999, p. 2 (hereafter cited as Lecea and Morales interview).

⁴³ Lecea and Morales Interview, p. 2.

⁴⁴ HRSA Web site, "Organization [and functions]," Office of Equal Opportunity and Civil Rights, p. 2.

⁴⁵ Claude Earl Fox, M.D., M.P.H., administrator, Health Resources and Services Administration, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 29, 1999 (re: request for informa-

tion), attachment to cover letter, p.1 (hereafter cited as HRSA, Response to Information Request).

⁴⁶ Ibid.

⁴⁷ Ibid.

⁴⁸ HCFA was the only OPDIV that submitted a memorandum of understanding with OCR by which certain civil rights functions are delegated. HHS, Health Care Financing Administration, "Memorandum of Understanding Between OCR and HCFA, 1979" (hereafter cited as HCFA, MOU). See HCFA, Response to Information Request, "Response to question #5."

- Resolving informal discrimination complaints by means of EEO counseling and/or alternative dispute resolution (ADR).
- Developing reports on the diversity of the agency work force and fairness in employment actions.
- Acting as an advocate for civil rights and related principles, including internally providing training, seminars, and technical assistance.⁴⁹

These functions appear to relate to HCFA's own employment and hiring practices. None of the OEOCR's stated functions directly indicates extramural civil rights responsibilities concerning, for example, HCFA's funding recipients' services to minorities and women or employment and hiring practices with respect to minorities and women.⁵⁰ In fact, according to the OEOCR EEO manager, the term "civil rights" was added to the name of the office only recently, in 1997.⁵¹

OEOCR has 20 staff members, but only 4 staff members are assigned to extramural civil rights matters.⁵² Written duties and responsibilities of high-level staff in the office are unclear in the extent to which extramural civil rights activities are included. Many of the duties and responsibilities concern only internal matters. The

position description for a GS-15 attorney-advisor, for example, states that the incumbent is the HCFA EEO officer, and as such he or she supervises employees "involved in the effective administration of a HCFA-wide EEO program for Central and Regional Office employees."⁵³

The attorney-advisor does engage in equal employment opportunity enforcement activities, however, he or she "[a]dministers a comprehensive complaints adjudication and analysis program for *all HCFA employees*,"⁵⁴ seemingly excluding complaints against programs funded by the agency. But in addition to receiving complaints and directing the investigation and resolution of complaints, the attorney-advisor's responsibilities include directing comprehensive reviews of allegations of discrimination, "which may be filed in writing by organizations or other third parties," and which are "unrelated to an individual complaint of discrimination."⁵⁵

Thus, HCFA's OEOCR does not appear to have the function of promoting extramural civil rights compliance among HCFA funding recipients, but some of the staff in the office do work that appears related to external civil rights activities. Some of the confusion as to whether the office performs extramural civil rights functions may arise because the authority for involvement in extramural civil rights issues is established through OCR's delegation to HCFA in its MOU rather than through legislation or regulations and because the office has only recently been broadened to include extramural civil rights. Moreover, although the delegation itself could be sufficient as a means of authorizing HCFA to conduct extramural civil rights enforcement efforts, the two agencies have not worked together to implement it or remove confusion as to the exact nature of HCFA's role, particularly whether or to what extent this role encompasses extramural civil rights enforcement. It appears

⁴⁹ HHS, Health Care Financing Administration, Office of Equal Opportunity and Civil Rights, Functional Statement, Apr. 19, 1997, p. 1 (hereafter cited as HCFA, OEOCR Functional Statement). See Ramon Suris-Fernandez, director, Office of Equal Opportunity and Civil Rights, Health Care Financing Administration, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 29, 1999 (re: request for information), "Response to question #1" (hereafter cited as HCFA, Response to Information Request).

⁵⁰ HCFA, OEOCR Functional Statement, p. 1.

⁵¹ Ramon Suris-Fernandez, director; Roderick Locklear; EEO manager; Alexia Redd, EEO specialist; Office of Equal Opportunity and Civil Rights; and Joe Tilghman, Regional administrator, Region VII; Health Care Financing Administration, telephone interview, Apr. 9, 1999, p. 2 (statement of Locklear) (hereafter cited as HCFA OEOCR interview).

⁵² Michael M. Hash, deputy administrator, HHS, Health Care Financing Administration, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, July 16, 1999 (re: health care report), attachment, p. 1 (hereafter cited as Hash letter); HHS, Health Care Financing Administration, Office of Equal Opportunity and Civil Rights, OEOCR, list of staff (hereafter cited as HCFA, OEOCR Staff); HCFA, OEOCR interview, p. 2 (statement of Suris-Fernandez). See HCFA, Response to Information Request, "Response to question #1."

⁵³ HHS, Health Care Financing Administration, Office of the Administrator, "Position Description, Agency Position No. 19692S, attorney-advisor, GS-905-15," p. 1 (hereafter cited as HCFA, GS-15 Attorney PD). See HCFA, Response to Information Request, "Response to question #3."

⁵⁴ HCFA, GS-15 Attorney PD, p. 1 (emphasis added).

⁵⁵ *Ibid.* Complaints against HCFA-funded programs are referred to the appropriate HCFA component and/or HHS/OCR. Several complaints have been sent to the U.S. Equal Employment Opportunity Commission because they had jurisdiction for the complaint allegations. Hash letter, attachment, p. 1.

the main problems are the clarity with which the instrument delegating authority delineates HCFA's role and both agencies' coordination and implementation efforts, particularly in clearly fashioning their objectives in involving HCFA in any extramural civil rights enforcement efforts and their ability to execute those objectives properly.

Regional Structures

Health Care Financing Administration

Most OPDIVS do not have formal responsibility for any civil rights enforcement activities. Because HCFA appears to have some extramural civil rights responsibilities, HCFA staff have more reason than other OPDIVS to interact with OCR staff. Most of the interaction between HCFA staff and OCR staff takes place at the regional level. HCFA has 10 regional offices, most of which are located in the same buildings as the HHS regional offices,⁵⁶ thus facilitating interactions between the two staffs. For example, several HCFA regional staff stated that they refer civil rights complaints to OCR, coordinate compliance matters with OCR,⁵⁷ and receive training from OCR.⁵⁸ HCFA regional staff also described joint projects with OCR staff, such as attending health fair events; providing ethnic language and interpretive resources; collaborating in the development of forms and civil rights policies and procedures; and addressing outreach issues.⁵⁹ One of HCFA's deputy regional administrators was the lead on a joint OCR/HCFA effort to develop and implement an Asian American Pacific Islander Hepatitis B project.⁶⁰

Two of the HCFA regions reported they had no projects with OCR.⁶¹ Further, the amount of time HCFA regional staff spend on civil rights activities is limited. Two HCFA regional offices were unable to estimate the amount of time

spent on extramural civil rights activities.⁶² Six regional offices estimated that they devote half or less of a full-time staff position (a full-time equivalent, or FTE) to civil rights and related activities.⁶³ Two regional offices have one or more FTEs devoted to civil rights activities.⁶⁴ But HCFA may be the only OPDIV with regional staff routinely engaged in extramural civil rights activities.⁶⁵

Other Operating Divisions

HCFA regional staff can interact easily with OCR staff because their regional offices are located in the same buildings as OCR's regional offices in most cases. However, not all OPDIVS have a regional office structure that provides such ready opportunities for interaction with OCR regional staff.⁶⁶ For example, FDA and IHS do not have the usual regional structures and

⁶² Ibid., "Region V" and "Region IX" responses to question 5.

⁶³ Ibid., "Region I," "Region III," "Region IV," "Region VII," "Region VIII," "Region X" responses to question 5.

⁶⁴ Ibid., "Region II," which estimated 2.05 FTEs; and "Region VI," which answered 1.0 FTE in responses to question 5.

⁶⁵ No other OPDIV provided regional responses to the Commission's request for information.

⁶⁶ Table 5.2 shows the proximity of OPDIVS' regional offices to OCR's regional offices. Eight of HCFA's regional offices are located in the same buildings as OCR's regional offices. Another is located within the same 5-digit zip code; and the last of the 10 is in the same city as an HHS/OCR regional office. ACF and the Office of Public Health and Science have regional offices corresponding to those of the headquarters HHS. Nine of them are in the same building and the 10th is within the same zip code. The AoA has only nine regional offices because Region III, typically located in Philadelphia, is handled out of the New York City office in Region II. Of the 9 AOA regional offices, 7 are in the same building as HHS' OCR regional offices, and the other two are within the same zip codes as the corresponding OCR offices. See *Regional Yellow Book*, pp. II-223 to II-259.

HRSA does not have the usual regional structure, but has good correspondence with OCR regional offices. HRSA has five clusters, rather than regions, and four of the five cluster offices are located in the same buildings as OCR regional offices. Furthermore, each cluster has field offices in one to three cities with a designated lead city. Of HRSA's cluster lead offices and field offices, 9 are in the same building and 10 are in the same zip code as OCR regional offices. See *Regional Yellow Book*, pp. II-244 to II-246.

Furthermore, four OPDIVS and the Office of Public Health and Science would have even greater proximity with OCR Regional Offices if OCR would move its Region VI office from 1200 Main Tower to 1301 Young Street, Dallas, TX. See *Regional Yellow Book*, pp. II-224, II-226, II-227, II-229, II-242, II-245.

⁵⁶ *Federal Regional Yellow Book* (Washington, DC: Leadership Directories, Inc.) vol. 7, no. 1 (winter 1999), II-223 to II-225 and II-240 to II-243 (hereafter cited as *Regional Yellow Book*).

⁵⁷ HCFA, Response to Information Request, "Region I," "Region IV," "Region V," "Region VII" responses to question 6.

⁵⁸ Ibid., "Region III" response to question 6.

⁵⁹ Ibid., "Region I," "Region VIII," "Region X" responses to question 6.

⁶⁰ Ibid., "Region I" response to question 6.

⁶¹ Ibid., "Region IV" and "Region V" response to question 6.

Table 5.2
Proximity of HHS and Operating Division Regional Offices

Operating division	Type of office	With respect to HHS regional offices: Number of operating divisions offices located in				Total number
		Same office	Same zipcode	Same city	Different city	
HCFA	Regional offices	8	9	10	0	10
ACF	Regional offices	9	10	10	0	10
PHS	Regional offices	9	10	10	0	10
FDA	Regional offices	0	1	4	2	5 or 6
	District offices	0	1	5	5	21
HRSA	Cluster/Lead city	4	5	5	0	5
	Cluster lead or field office	9	10	10	0	10
AoA	Regional offices	7	9	9	0	9

SOURCE: Compiled from the *Federal Regional Yellow Book* (Washington, DC: Leadership Directories, Inc.) vol. 7, no. 1 (winter 1999) II-23 to II-259. Note that NIH, CDC, AHCPR, and ATSDR do not have regional offices.

lack proximity with OCR regional offices. FDA has five regions with six regional offices. None of the FDA regional offices is located in the same building as an OCR office, although four are in the same city. FDA also has 21 district offices, none of which is located in the same building and only 5 of which are in the same cities as OCR regional offices.⁶⁷ IHS has a western headquarters and 12 area offices. Because their locations are determined by the locations of Indian reservations and tribes, most are in the western half of the Nation. Only one area office is even located in the same State as any OCR regional office.⁶⁸

The lack of proximity between certain OPDIVS' regional offices and OCR regional offices precludes casual, day-to-day encounters between the two staffs and to some extent could restrict interactions on more formal activities. The issue is less critical when OPDIVS have no civil rights enforcement responsibilities. However, certain activities, such as training and technical assistance for FDA staff to assume more extramural civil rights responsibilities, will have to be formal and accompanied with intensive followup efforts to overcome these barriers.

⁶⁷ *Regional Yellow Book*, pp. II-236 to II-240 and II-223 to II-226.

⁶⁸ *Regional Yellow Book*, pp. II-246 to II-256.

OPDIVS' Knowledge of Civil Rights Regulations and Guidance

To demonstrate their awareness of OCR regulations and guidance, the Commission asked OPDIVS to provide copies of their current regulations, directives, policy guidelines, and procedures that govern their civil rights implementation and enforcement efforts. Among the documents OPDIVS provided, or referred to, in response to this request were the following:

- HHS regulations concerning nondiscrimination on the basis of race, color, or national origin,⁶⁹ sex,⁷⁰ age,⁷¹ and handicap.⁷²
- OCR guidance on the application of nondiscrimination provisions to persons with limited English proficiency.⁷³
- Six OCR fact sheets explaining to the general public how to file complaints of discrimination on the basis of race, color, national origin, sex, age, disability, and HIV infection, AIDS, or related conditions.⁷⁴

⁶⁹ 45 CFR § 80.3(a) (1998); 42 CFR § 124.9, Subpart A (1998).

⁷⁰ 45 CFR § 86.1 (1998).

⁷¹ *Id.* at 91.11 (1998).

⁷² *Id.* at § 84 (1998).

⁷³ HHS, OCR, "OCR Guidance to Staff on Title VI Nondiscrimination Provisions—Limited English Proficiency (LEP)," Jan. 29, 1998 (hereafter cited as OCR, "Guidance Memorandum on Limited English Proficiency").

⁷⁴ The OCR fact sheets include "Know Your Civil Rights" which also tells beneficiaries how to file a complaint of discrimination; "Your Rights Under Title VI of the Civil Rights

- A July 1993 pamphlet for recipients and beneficiaries, "Civil Rights Under PHS Grants and Contracts," explaining nondiscrimination requirements under civil rights statutes in effect for grants, cooperative agreements, and contracts; and listing OPDIV offices with civil rights responsibilities and Federal agencies with enforcement responsibility.⁷⁵
- The *PHS Grants Policy Statement*,⁷⁶ or the more recent *NIH Grants Policy Statement*,⁷⁷ explaining civil rights policies and requirements to grant applicants.
- OCR's *Case Resolution Manual* containing examples of civil rights complaints that HHS/OCR has used as training material.

Based on their responses to Commission's request, each OPDIV differs in its awareness and understanding of these documents. The numbers of OPDIVS that demonstrated awareness of these HHS and OCR documents pertaining to civil rights by either referring to them or providing them to the Commission are shown in table 5.3. Of nine OPDIVS from which the Commission requested documents, only four provided most of OCR's nondiscrimination regulations,⁷⁸ three provided or referred to the guidance on nondiscrimination with respect to

Act of 1964"; "Community Service Assurance Under the Hill-Burton Act"; "Your Rights Under the Age Discrimination Act"; "Your Rights as an Individual with Handicaps Under section 504"; and "Your Rights as A Person with HIV Infection, Aids, or Related Conditions."

⁷⁵ HHS, Public Health Service, "Civil Rights Under PHS Grants and Contracts," July 1993. See NIH Response to Information Request, tab 10, or SAMHSA, Response to Information Request, tab 17.

⁷⁶ HHS, *PHS Grants Policy Statement*, DHHS publication no. (OASH) 94-50,000 (Rev.) Apr. 1, 1994 (hereafter cited as *PHS Grants Policy Statement*).

⁷⁷ HHS, National Institutes of Health, *NIH Grants Policy Statement*, NIH publication no. 99-8, October 1998 (hereafter cited as *NIH Grants Policy Statement*).

⁷⁸ See HCFA, Response to Information Request, tab 13; NIH, Response to Information Request, tab 9; FDA, Response to Information Request, tab 9; HHS, Health Resources and Services Administration, "HRSA Policy for Monitoring Civil Rights Compliance of Financial Assistance and Acquisition Programs," HRSA circular no. 92.05 (Sept. 18, 1992), p. 2 (hereafter cited as HRSA circular no. 92.05). See HRSA, Response to Information Request, tab 2; CDC and SAMSHA only provided or referred to nondiscrimination regulations for title VI of the Civil Rights Act. CDC, Response to Information Request, tab D; SAMHSA, Response to Information Request, tab 10.

limited English proficiency,⁷⁹ and three either provided or referred to at least some of the OCR fact sheets on civil rights.⁸⁰ Three OPDIVS provided or referred to the pamphlet, "Civil Rights Under PHS Grants and Contracts."⁸¹ Four provided either part or all of a grants policy manual.⁸² One OPDIV provided the *Case Resolution Manual*.⁸³

Two of the OPDIVS—IHS and AoA—provided none of the documents⁸⁴ and otherwise demonstrated a lack of understanding of their extramural civil rights responsibilities. The director of IHS' Equal Employment Opportunity and Civil Rights Staff stated that her staff do no work concerning extramural civil rights, but work only on equal employment opportunity. She said that she does not refer any complaints to OCR because it does not have jurisdiction over tribes.⁸⁵ Yet in the IHS response to the Commission's request for documents and information on extramural civil rights, the OPDIV provided correspondence on suspected patterns of discrimination against American Indians and Alaskan Natives involving State and local programs or State and local administrations of federally funded

⁷⁹ See NIH, Response to Information Request, tab 9; HRSA, Response to Information Request, tab 7; SAMSHA, Response to Information Request, tab 9.

⁸⁰ See HCFA, Response to Information Request, tab 13; FDA, Response to Information Request, tab 9; SAMSHA Response to Information Request, tab 10.

⁸¹ See NIH, Response to Information Request, tab 10; SAMHSA, Response to Information Request, tab 17; CDC, Response to Information Request, tab D.

⁸² See SAMHSA, Response to Information Request, tab 17, CDC, Response to Information Request, tab G, and HRSA, Response to Information Request, tab 10, all of which included the *PHS Grants Policy Statement*; and NIH, Response to Information Request, tab 9, which included the *NIH Grants Policy Statement*.

⁸³ HHS, OCR, *Case Resolution Manual*, Dec. 15, 1995. See NIH Response to Information Request, tab 9.

⁸⁴ See Jeanette C. Takamura, Assistant Secretary, Administration on Aging, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Jan. 15, 1999 (hereafter cited as AoA, Response to Information Request); IHS, Response to Information Request, tab 10.

The IHS provided two USCCR publications—*American Indian Civil Rights Handbook*, September 1980, and *The Indian Civil Rights Act*, June 1991—and not any OCR guidance. See IHS, Response to Information Request, tab 10.

⁸⁵ Heftel, Mar. 1, 1999, conversation. See also Cecilia Heftel, EEO director, Indian Health Service, HHS, telephone conversation with Frederick D. Isler, Office of Civil Rights Evaluation, USCCR, Apr. 20, 1999.

Table 5.3**Operating Divisions' Awareness of HHS' Civil Rights Regulations, Guidance, and Policies**Operating divisions that demonstrated awareness of civil rights related document(s)

	Number	Percent
Most of the HHS regulations on nondiscrimination on the basis of race, color or national origin, sex, handicap, and age (including community service assurance regulations)	4	44%
HHS, OCR guidance memorandum on the application of title VI nondiscrimination provisions for persons with limited English proficiency	3	33%
Half or more of the six HHS fact sheets on discrimination on the basis of race, color or national origin, sex, age, handicap, or HIV infection, AIDS or related disease (including community service assurance)	3	33%
Pamphlet, "Civil Rights Under PHS Grants and Contracts"	3	33%
Grants Policy Statement	4	44%
Case Resolution Manual	1	11%

SOURCE: Documents submitted in response to information request.

programs.⁸⁶ The response also included a memorandum of agreement with OCR clearly identifying IHS' responsibilities to notify OCR of instances of discrimination and to enforce requirements with private health contractors who were denying services to their American Indian and Alaskan Native clients.⁸⁷ Finally, the IHS documents included grant application kits requiring that the applicant (or the applicant's organization) sign an assurance of compliance with all Federal statutes relating to nondiscrimination.⁸⁸ This assurance is the mechanism by which

all recipients of Federal assistance are accountable for complying with civil rights statutes.⁸⁹

AoA's response to the Commission's request indicated that the enforcement of nondiscrimination laws regarding access to health care for women and members of racial and ethnic minority groups is irrelevant given AoA's mission. The Assistant Secretary for Aging stated that the AoA "does not provide *direct* access to health care, health care financing, or conduct medical

⁸⁶ Michael E. Lincoln, acting director, Indian Health Services, HHS, memorandum to Principal Deputy Assistant Secretary for Health, HHS, Mar. 11, 1994 (re: civil rights priorities) (hereafter cited as Lincoln memorandum).

⁸⁷ Everett R. Rhoades, M.D., Assistant Surgeon General, director, Indian Health Service, HHS, memorandum to IHS executive staff, area/program directors, and headquarters division directors, May 2, 1986 (re: Three Party Agreement on Indian Access to Health Programs), pp. 4-5 (hereafter cited as IHS, Three Party Agreement).

⁸⁸ HHS, Indian Health Service, "Fiscal Year 1999 Application Kit for Tribal Management Grants for American Indian and Alaska Native Tribes and Tribal Organizations," Jan. 5, 1999, p. 25 and "Assurances—Non-Construction Programs" (Standard Form 424B); HHS, Indian Health Service, "Fiscal Year 1999 Program Announcement and Application Kit for the Indian Health Service Tribal Recruitment and Retention of Health Care Professionals into Indian Health Programs,"

April 1999, p. 25 and "Assurances—Non-Construction Programs" (Standard Form 424B); HHS, Indian Health Service, "Fiscal Year 1999 Program Announcement and Application Kit for the Indian Health Service Matching Grants for Health Professions Scholarships to Indian Tribes," April 1999, p. 25 and "Assurances—Non-Construction Programs" (Standard Form 424B). See IHS, Response to Information Request. Two other such application kits are: HHS, Indian Health Service, "Fiscal Year Application Kit for FY 1999 Tribal Self-Governance Demonstration Program Planning Cooperative Agreements," Mar. 15, 1999; and HHS, Indian Health Service, "Fiscal Year Application Kit for FY 1999 Tribal Self-Governance Demonstration Program Negotiation Cooperative Agreements," Mar. 15, 1999. They also contain the "Assurance—Non-Construction Programs" (Standard Form 424B). See Michael H. Trujillo, Assistant Surgeon General, director, Indian Health Service, HHS, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, July 2, 1999.

⁸⁹ The assurance form is discussed in greater detail later in this chapter.

research,"⁹⁰ failing to recognize that the OPDIV must promote civil rights compliance in health services it provides indirectly through its funding recipients. According to the *Catalog of Federal Domestic Programs*, the AoA administers numerous special programs for the aging through State grants.⁹¹ Because of administering these programs, the AoA has the same responsibility to support OCR's enforcement endeavors through whatever activities OCR deems appropriate, typically outreach and technical assistance. The lack of understanding of extramural civil rights responsibilities on the part of AoA and IHS demonstrates that OCR needs to conduct training on these responsibilities.

The general lack of OPDIVS' awareness of civil rights related documents is disturbing. Yet, at the same time, the information contained in these documents is either too technical, as in the case of the regulations, or too superficial to be useful to OPDIV staff or funding recipients in understanding compliance. The Grants Policy Statements provide a lengthier format which could recommend ways grant applicants and grantees should attempt to overcome adverse effects on the quality of health care for minorities and women. However, as will be seen, they provide recipients little how-to help in terms of ensuring civil rights compliance, such as how to assess whether discrimination is present and methods of overcoming adverse effects.

⁹⁰ AoA, Response to Information Request (emphasis added).

⁹¹ For example, these programs include "Programs for Prevention of Elder Abuse, Neglect, and Exploitation," which develop and enhance comprehensive and coordinated programs for the prevention and treatment of such problems; "Long Term Care Ombudsman Services for Older Individuals," a program that develops service systems whereby an ombudsman investigates and resolves complaints on behalf of residents of long-term care facilities and promotes policies and practices that improve the quality of care in these facilities; "Disease Prevention and Health Promotion Services" for the aging, which provide periodic preventive health services at senior centers or alternative sites; "Nutrition Services," a program for local projects that give older Americans meals 5 or more days a week to maintain their health, independence and quality of life; "In-Home Services for Frail Older Individuals," a program for in-home supportive services, personal care, and other services for older victims of Alzheimer's disease and related disorders with neurological and organic brain dysfunctions and for their families; and "Allotments for Vulnerable Elder Rights Protection Programs," which supports State outreach, counseling, and assistance programs for insurance and public benefits. 1998 CFDA, pp. 963-70.

The *PHS Grants Policy Statement* is a comprehensive manual explaining the types of grant applications, the award process, allowable costs, and postaward administration.⁹² A section on "Preaward Policies and Considerations" explains the civil rights requirements with respect to race, ethnicity, disabilities, age, and gender.⁹³ The text of guidance on these aspects of civil rights states the nondiscrimination provisions; identifies the statute and regulations they come from; stresses that these provisions apply to programs or activities receiving Federal financial assistance, whether directly or under a subgrant or contract arrangement; and tells about the assurance that recipients of funds must sign.⁹⁴

Despite the importance of this medium for explaining civil rights to grant applicants, use of the document is likely to wane, and the chance of updating it or expanding the civil rights coverage is bleak. The Office of the Assistant Secretary of Health last issued the *PHS Grants Policy Statement* in April 1994,⁹⁵ before the reorganization that placed the OPDIVS directly under the HHS Secretary, rather than the Office of the Assistant Secretary.⁹⁶ Since then, the Office of the Secretary has not issued any updates to this manual.

In 1998 NIH issued the *NIH Grants Policy Statement* to provide its grantees with updated information.⁹⁷ But NIH does not have the authority to impose its policy statement on other OPDIVS,⁹⁸ and other OPDIVS use the less recent *PHS Grants Policy Statement* even though the *NIH Grants Policy Statement* is an improvement.

The *NIH Grants Policy Statement* uses language that is similar to that of the older PHS

⁹² *PHS Grants Policy Statement*, "table of contents."

⁹³ *Ibid.*

⁹⁴ *Ibid.*, pp. 4-2 and 4-3.

⁹⁵ *Ibid.*, cover.

⁹⁶ 60 Fed. Reg. 56,605-06 (1995).

⁹⁷ *NIH Grants Policy Statement*, "Background and Supersession," p. ii.

⁹⁸ Ruth Kirschstein, deputy director; Donna Dean, Office of the Director; Vivian Pinn, Office of Research on Women's Health; Jean Flagg-Newton, Office of Research on Minority Health; Diana Jaegar, Office of Extramural Research; Pedro J. Morales, Office of Equal Opportunity; Pat Abell and Donna Comstock, Office of Management Assessment; National Institutes of Health, HHS, entrance conference in Rockville, MD, Mar. 24, 1999 (statement of Jaegar) (hereafter cited as NIH entrance conference).

version regarding the four nondiscrimination statutes (e.g., race/ethnicity, sex, age, disabilities).⁹⁹ In addition, the NIH manual refers to the NIH Guidelines on the Inclusion of Women and Minorities as Subjects of Clinical Research, stating that human subjects research must comply with these guidelines.¹⁰⁰ Applicants' proposed research plans are evaluated according to these guidelines before NIH makes an award and awards may be denied if the Guidelines are not followed.¹⁰¹ Grantees also are required to report annually on the gender, race, and ethnicity of individuals enrolled in their research study.¹⁰² The manual implies that a noncompeting continuation request could be denied if the guidelines have not been followed.¹⁰³

Compliance with the *NIH Grants Policy Statement* is a formally stated condition for accepting an NIH grant. Because NIH considers the policy statement as contractual terms, the manual provides scant guidance on how to achieve civil rights compliance, apart from the inclusion of minorities and women as research subjects. NIH has provided a how-to guide in another document that is not a condition for receiving a grant, the "Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research."¹⁰⁴ The "Outreach Notebook" contains advice on how to establish and maintain communication with participants in federally assisted programs, their families and communities to include them in research studies.¹⁰⁵ For example, it discusses formal and informal methods of communication and

⁹⁹ *NIH Grants Policy Statement*, p. II-23. Some language included in the older *PHS Grants Policy Statement* but not in the *NIH Grants Policy Statement* is the following: "All PHS grantees are encouraged to adopt practices that will eliminate sex discrimination and encourage sex fairness, including but not limited to using language that represents both genders, avoiding sex stereotyping, and representing women equitably in leadership and policy-making positions." *PHS Grants Policy Statement*, p. 4-2. This policy is presumably covered by the requirements for inclusiveness in the research design described below.

¹⁰⁰ *NIH Grants Policy Statement*, p. II-22.

¹⁰¹ *Ibid.*

¹⁰² *Ibid.*

¹⁰³ *Ibid.*

¹⁰⁴ HHS, National Institutes of Health, "Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research," NIH publication no. 97-4160 (hereafter cited as NIH Outreach Notebook).

¹⁰⁵ *Ibid.*, pp. 18-19.

suggests using an outreach educator to maintain contact with community leaders and devise strategies for bolstering retention of subjects in the study.¹⁰⁶

In conclusion, it appears as if the OPDIVS have little knowledge of the guidance OCR provided on extramural civil rights matters that explains civil rights laws and provides contacts for persons who believe themselves to be victims of discrimination. Guidance that helps grant applicants or providers with strategies for better achieving compliance with civil rights laws does not appear to be disseminated by HHS. On the other hand, some OPDIVS have developed useful documents, such as NIH's "Outreach Notebook," which is directed toward NIH grant applicants, particularly those conducting clinical trials.

Extent of OPDIVS' Extramural Civil Rights Enforcement Activities

Although their organizational structures and levels of interaction with OCR may not be conducive to conducting civil rights activities, all of the OPDIVS are performing some form of extramural civil rights functions. It appears the only formally proscribed extramural enforcement responsibility of the OPDIVS is the assurance of civil rights compliance that recipients must provide before receiving Federal funds. However, the operating divisions can also affect the quality of OCR's enforcement activities to ensure accessibility to health care for minorities and women in other ways.¹⁰⁷

Formal Agreements with HHS/OCR

OCR can delegate to the operating divisions responsibilities for enforcing civil rights among their recipients of grants and contracts. OCR can delegate any such authority through an MOU with the OPDIV's appropriate civil rights office. Indeed, an MOU is appropriate for OPDIVS to collect the additional information on grant applicants' past civil rights performance before making awards, as was recommended by the HHS Civil Rights Review Team.¹⁰⁸

Currently, only two OPDIVS have formal agreements with OCR: HCFA, which adminis-

¹⁰⁶ *Ibid.*

¹⁰⁷ USCCR, *Federal Title VI Enforcement*, p. 220.

¹⁰⁸ HHS, *Report of the HHS Civil Rights Review Team*, September 1993, pp. 24-25 (hereafter cited as HHS, *Review Team Report*).

ters the medicaid and medicare programs,¹⁰⁹ and IHS.¹¹⁰ FDA is negotiating for a memorandum of understanding with OCR and expects to have one in place by June 1999.¹¹¹ HRSA has been negotiating a partnership with OCR, but only in one region.¹¹² It is unclear whether OCR has or will delegate authority to an OPDIV to conduct preaward or postaward desk audits in any of these agreements.

HCFA's Memorandum of Understanding

The memorandum of understanding between the Health Care Financing Administration and OCR has been in effect since 1979.¹¹³ It delegated HCFA seemingly broad extramural responsibilities for enforcing civil rights among recipients of its grants and contracts. It states that "to make civil rights an essential and integral part of every program in the Department," HCFA must "seek and select program policies and procedures which can assist in achieving . . . the objectives of the civil rights statu[t]es"; "take positive action to remove barriers that tend to exclude people from the benefits of its programs because of race, color, national origin or handicapped status"; "help prevent discrimination before it occurs"; and "assist recipients of HCFA funds (*Medicaid/Medicare providers and Medicaid State agencies*) in compliance with the civil rights authorities. . . ."¹¹⁴

The MOU further dictates tasks that HCFA must carry out, including incorporating civil rights concerns into program reviews and audits "to assure that benefits and services are delivered equitably to eligible minority . . . persons"; establishing data collection on minority program

participation "to enable program officials to determine if grant applicants or recipients are violating civil rights requirements"; providing "technical experts and assistance to . . . recipients about policies, practices and procedures for civil rights compliance" and referring "unresolved or complex civil rights compliance issues to the [Departmental] Office for Civil Rights"; reviewing "program regulations, directives and instructions" to ensure accord with civil rights authorities; identifying "recipients' civil rights technical assistance . . . needs and approve contracts to meet those needs"; providing program and recipient staff "orientation and training programs on civil rights requirements"; using "financial resources to support civil rights equity, to prevent acts of discrimination and to assist in the remedy of past acts adversely affecting minority . . . persons"; and monitoring existing civil rights compliance agreements as arranged with OCR.¹¹⁵

The MOU also states the ways in which the departmental Office for Civil Rights will support HCFA. OCR will develop "civil rights standards and procedures for inclusion in HCFA . . . program reviews and audits"; develop "guidelines for . . . HCFA . . . [to collect] and review . . . civil rights data to identify civil rights compliance problems"; "[c]onduct training programs . . ."; "[p]rovide civil rights technical assistance . . ."; and "[e]stablish programs to explain civil rights compliance to HCFA recipients/providers"; "[e]stablish guidelines for review of HCFA program regulations, directives and instructions to assure support for the Department's civil rights authorities"; [d]evelop . . . financial assistance projects to support civil rights compliance"; and "[i]dentify existing civil rights agreements to be monitored by HCFA."¹¹⁶ OCR regional offices "will inform their counterpart HCFA regional offices of upcoming OCR compliance reviews and complaint investigations pertaining to HCFA providers and furnish HCFA with copies of Letters of Findings." In turn, "HCFA will provide OCR with provider agreement renewal dates. . . ."¹¹⁷

For the most part, the language of the MOU is vague. The MOU does not contain any language about HCFA conducting any preaward,

¹⁰⁹ HCFA, MOU.

¹¹⁰ IHS, Three Party Agreement.

¹¹¹ Lecea and Morales interview, pp. 2, 5 (statements of Lecea and Morales).

¹¹² Douglas O. Woods, acting field coordinator, Health Resources and Services Administration, HHS, draft memorandum to Frank Martinez, deputy director, OCR, HHS, April 1996 (re: developing a partnership between OCR and HRSA) (hereafter cited as Woods draft memorandum). See Carmen Palomera Rockwell, regional manager, Region X, OCR, HHS, memorandum to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, Dec. 15, 1998 (re: health care project), HHS Information Request, item H-2-e (hereafter cited as OCR Region X Response to Information Request).

¹¹³ See HCFA, MOU.

¹¹⁴ Ibid. (emphasis in original).

¹¹⁵ Ibid., pp. 2-3.

¹¹⁶ Ibid., pp. 3-4.

¹¹⁷ Ibid., pp. 4-5.

postaward, or onsite reviews of compliance. In addition, it does not direct HCFA to collect information that might be used by OCR for such reviews. All such activities remain the responsibility of OCR. However, the MOU does spell out a number of civil rights activities HCFA should be carrying out. Yet the document does not appear to be used to guide HCFA civil rights activities, and is not well known among HCFA staff. For example, when asked about the MOU with OCR, none of the HCFA regional office heads, whose staff have the most direct contact with HCFA funding recipients, made reference to the MOU.¹¹⁸

The director of HCFA's OEOCR explained that his office has done little toward meeting the responsibilities stated in the MOU.¹¹⁹ For example, according to the director, OEOCR has not established a data collection system on the participation of minorities in HCFA programs to determine if providers are violating civil rights requirements.¹²⁰ OEOCR furnishes providers technical experts or assistance about policies, practices, and procedures for civil rights compliance, but not on a regular basis.¹²¹ The director of OEOCR stated that his office also has not provided recipients with technical assistance on civil rights.¹²² Furthermore, the director explained that OEOCR does not have any way of knowing how well providers are doing with respect to civil rights because any information on this is sent directly to OCR.¹²³

¹¹⁸ HCFA, Response to Information Request, "Region I" through "Region X," responses to question 1. In contrast several Regional Office heads provided HCFA's Civil Rights Compliance Policy Statement. Nancy-Ann Min DeParle, administrator, HHS, memorandum to HCFA Leadership, HCFA Civil Rights Compliance Policy Statement, Apr. 9, 1998 (hereafter cited as HCFA, 1998 Civil Rights Compliance Statement). See HCFA, Response to Information Request, "Response to question #7," "Region VI," "Region VIII," "Region IX."

¹¹⁹ HCFA, OEOCR interview, p. 2.

¹²⁰ *Ibid.*, p. 3 (statement of Suris-Fernandez).

¹²¹ *Ibid.*

¹²² *Ibid.* Note that regional offices may be providing some technical assistance or training on hospital dumping issues, for example, but those have more to do with patient rights than civil rights. *Ibid.*, p. 4 (statement of Tilghman). Mr. Locklear indicated that some efforts to identify providers' technical assistance needs were made in the early 1980s soon after the MOU was established, and the effort resulted in a booklet and some conferences. *Ibid.*, p. 4 (statement of Locklear).

¹²³ *Ibid.*, p. 4 (statement of Suris-Fernandez).

Since the name of the office was changed from Office of Equal Opportunity to OEOCR in 1997, staff have begun reviewing program regulations, directives, and instructions to ensure that they support the Department's civil rights authorities.¹²⁴ They have disseminated HCFA's Civil Rights Compliance Policy Statement and have been consulting with OCR to develop a "checklist" that can be used during program reviews to make program managers more accountable and provide them a tool for preventing noncompliance.¹²⁵ A recent OEOCR undertaking has been to initiate civil rights training for 2,400 HCFA headquarters and regional staff. OCR staff will be the trainers for the 60 planned sessions.¹²⁶

The director of HCFA's OEOCR said that his staff need more information on how to implement the MOU and process complaints, including specific complaints filed against funding recipients.¹²⁷ He stated that communication between HCFA and OCR needs to be improved. For example, HCFA and OCR typically communicate only during preaward reviews.¹²⁸ At the same time, OCR needs technical assistance from HCFA staff to better understand how its programs operate. The OEOCR director had high hopes for establishing better communication through the agencywide training that OCR was giving. However, he wanted to establish an even closer relationship with OCR through a new MOU.¹²⁹ OEOCR staff explained that they wanted to help expedite OCR's enforcement activities by providing the "muscle" to get providers to submit the documentation OCR needs for its reviews.¹³⁰

In October 1999, after HCFA has completed its massive training effort and staff are better informed about civil rights enforcement, OEOCR plans to negotiate a new MOU with OCR.¹³¹ OEOCR staff hope a new MOU will have clearer

¹²⁴ *Ibid.*, p. 2 (statement of Locklear).

¹²⁵ *Ibid.*, p. 2 (statement of Locklear). See HCFA, 1998 Civil Rights Compliance Statement. See also HCFA, Response to Information Request, "Region VI," "Region VIII," "Region IX."

¹²⁶ HCFA OEOCR interview, p. 7 (statement of Suris-Fernandez).

¹²⁷ *Ibid.*, p. 6 (statement of Suris-Fernandez).

¹²⁸ *Ibid.*, p. 7 (statement of Tilghman).

¹²⁹ *Ibid.*, p. 6 (statement of Suris-Fernandez).

¹³⁰ *Ibid.* (statement of Locklear).

¹³¹ *Ibid.*, p. 6.

language about HCFA responsibilities, will build a closer relationship with OCR, provide a means by which HCFA can expedite complaints processing or compliance reviews for OCR, and reflect the 20 years of program changes that have occurred since the last MOU was signed.¹³²

HCFA's MOU with OCR also includes several responsibilities of OCR. HCFA staff had difficulty identifying ways in which OCR was fulfilling the responsibilities stated in the MOU. OCR is working with HCFA staff to develop the "checklist" that can be used in regular program reviews and audits.¹³³ One HCFA regional administrator stated that, in his region, OCR meets with advocacy groups and holds regional meetings or briefings with beneficiaries to explain civil rights compliance to HCFA providers.¹³⁴ But OCR had not developed any guidelines for the collection and review of civil rights data to identify civil rights compliance problems.¹³⁵ OEOCR staff implied that the inadequacy of the current data system was only now being recognized.¹³⁶

IHS' Three-party Agreement

The Indian Health Service (IHS) has been concerned that American Indians and Alaska Natives are eligible for the same health care services or payments for services as others, yet they are often refused such services and referred to IHS services, which are intended to provide only residual medical care and services. IHS has had a three-party agreement involving IHS, OCR, and HCFA to address the civil rights enforcement of this issue since 1974. The agreement was updated in 1986.¹³⁷

The agreement contains the following policy statements: IHS services are not a primary health service resource, but a residual program to address gaps in availability and accessibility;

¹³² Ibid. (statements of Suris-Fernandez, Locklear, and Tilghman).

¹³³ Ibid., pp. 2, 9 (statement of Locklear).

¹³⁴ Ibid., p. 6 (statement of Tilghman).

¹³⁵ Ibid., p. 5.

¹³⁶ OCR recently requested medicaid data for a project involving a specific nursing home and found that the data were not adequate for analyzing a single nursing home. HCFA OEOCR staff had only learned of the inadequacy of the data a few days before the April 1999 interview. Ibid. (statement of Locklear).

¹³⁷ IHS, Three Party Agreement, pp. 1-3.

American Indians and Alaska Natives have the same rights to receive services under State plans, such as medicaid, as do all other eligible individuals; and refusing to provide health services or payments to American Indians or Alaska Natives on the ground that IHS services are available is discrimination.¹³⁸ It further lists the responsibilities of OCR, HCFA, and IHS to implement this policy.

According to the agreement, OCR must designate headquarters and regional staff to serve as liaisons with IHS for civil rights complaints and activities related to the agreement. It must collect sufficient information from State and local agencies and medical service providers to monitor civil rights compliance. It must investigate any complaints or information IHS forwards regarding complaints of this type of discrimination and proceed with other appropriate enforcement activities. Finally, OCR must require State and local agencies that administer medical services programs to communicate the availability of services to American Indian and Alaska Native communities.¹³⁹

The agreement requires IHS to coordinate outreach with other groups and organizations to inform American Indians and Alaskan Natives about their eligibility for health services payment programs. It must assist American Indians and Alaskan Natives with obtaining the necessary certifications for these programs and in filing complaints with OCR. IHS must enforce requirements of contractors concerning third-party payment for services rendered to eligible American Indians and Alaskan Natives and notify OCR of instances of health care providers' or contractors' noncompliance. IHS must also help identify the number of American Indians and Alaska Natives eligible for various federally assisted services so that service to them can be monitored.¹⁴⁰ HCFA responsibilities identified in the agreement are: informing State agencies administering the medicaid program about the policy on the eligibility of American Indians and Alaskan Natives, ensuring that State plans and practices do not conflict with this policy, providing technical assistance to develop procedures to avoid noncompliance, and notifying OCR of in-

¹³⁸ Ibid.

¹³⁹ Ibid.

¹⁴⁰ Ibid., pp. 4-5.

stances where State or local agencies deny American Indians or Alaskan Natives eligibility in noncompliance with the policy.¹⁴¹

The three-party agreement clarifies IHS and HCFA responsibilities for extramural civil rights activities, yet does not delegate any authority for conducting complaints investigations or compliance reviews. Thus, it does not extend the OPDIV's responsibilities any further. OCR's responsibilities, apart from providing headquarters and regional liaisons, are nothing more than the enforcement activities for which it is responsible even in the absence of an agreement.

The three-party agreement does not appear to have overcome discrimination against American Indians and Alaskan Natives in health service payment programs. In a 1994 memorandum, IHS concluded that OCR was not enforcing civil rights with respect to American Indians.¹⁴² It noted first that the 1986 agreement was a compromise—IHS wanted OCR to establish an "Indian Desk" rather than liaisons. Second, OCR does not give American Indian and Alaskan Native issues a high priority. Third, OCR has given little attention to incidents of apparent discrimination against American Indians and Alaskan Natives as indicative of statewide institutionalized, discriminatory attitudes, policies, and procedures.¹⁴³

HRSA Partnership with OCR in Region X

Staff in the Health Resources and Services Administration Region X office have negotiated a partnership with OCR's Region X staff.¹⁴⁴ The

partnership was developed in response to a directive of the Secretary in which she stated that she considered it a priority to ensure that "Department funds are dispersed and programs are operated without discrimination based on racial, national origin, disability condition, sex, age or other prohibited bias."¹⁴⁵ HRSA staff anticipated that the partnership would commit HRSA to working with OCR "to develop an effective technical assistance guide for Migrant and Community Health Centers"; and "to develop a long range strategy for expanding . . . joint efforts to other community providers and . . . HRSA programs."¹⁴⁶ It also would obligate HRSA to work with health centers to correct any deficiencies the centers identify with respect to their staffing, facilities or services.¹⁴⁷ The partnership initiative included the development of a civil rights compliance guide for HHS grantees "which could be used by grantees to conduct a civil rights self-assessment."¹⁴⁸ The guide met with resistance from some staff.¹⁴⁹ This resistance was accompanied with a challenge to the status of the partnership given that there was no MOU.¹⁵⁰

Some of the objections to HRSA's civil rights compliance guide were raised because the self-assessment was an ongoing monitoring tool for grantees who have already received an award;¹⁵¹ thus, the guide might not be effective as a preaward instrument. One HRSA regional staff person argued, "The grantees are already in compliance with civil rights laws and should not be burdened with a self-assessment. They sign Assurance forms and we should take them at their

¹⁴¹ *Ibid.*, pp. 5–6.

¹⁴² Lincoln memorandum.

¹⁴³ *Ibid.* In August 1997, OCR issued a brief policy statement on consultation with Native American governments. The policy statement provides guidelines and procedures for conducting compliance and technical assistance. The statement briefly outlines the criteria used to identify issues affecting this population's access to programs operated by recipients of Federal financial assistance from HHS. HHS, OCR, "Policy Statement for Consultation with American Indian and Alaska Native Governments," Aug. 28, 1997. However, beyond this brief policy statement, the Commission found no evidence that OCR has conducted compliance reviews in the health care context focused on Native American communities or that it has developed a strong technical assistance and outreach and education program targeted toward this population.

¹⁴⁴ See Woods draft memorandum; Frank Martinez, deputy director, Office of Civil Rights, Region X memorandum to Douglas O. Woods, acting field coordinator, HRSA, Region X, Apr. 1, 1996 (re: status of the partnership between OCR and

HRSA) (hereafter cited as Martinez memorandum). See OCR Region X Response to Information Request, item H-2-e.

¹⁴⁵ Douglas O. Woods, chief, Health Services Delivery Branch, Region X, and Frank V. Martinez, deputy director, OCR, Region X, letter to Benjamin Flores, executive director, Columbia Valley Community Health Services, May 27, 1998, p. 1 (quoting Donna Shalala, memorandum to the heads of the operating divisions) (re: revitalization of the commitment of the HHS (DHHS) to the enforcement of civil rights obligations both within the Department and among program grantees) (hereafter cited as Woods and Martinez letter, May 27, 1998).

¹⁴⁶ See Woods draft memorandum.

¹⁴⁷ *Ibid.*

¹⁴⁸ Martinez memorandum.

¹⁴⁹ *Ibid.*

¹⁵⁰ *Ibid.*

¹⁵¹ *Ibid.*

word.”¹⁵² At the same time, at least some grantees found the compliance guide “a very useful tool” because “some grantees sign the Civil Rights Assurance forms because they form part of the funding package, not because they are consciously aware that their signature implies provision of health services in a nondiscriminatory manner.”¹⁵³ Seven grantees who completed an early version of the guide reported that “the exercise was effective in raising their awareness of civil rights issues and requirements,” and that “they learned new, cost effective ways of serving patients that are covered by civil right[s] regulations.”¹⁵⁴

Despite these concerns, the Region X partnership remained intact.¹⁵⁵ OCR and HRSA pursued their plan to develop a civil rights compliance guide. As of May 1998, HRSA’s Region X was asking grantees to test voluntarily its civil rights self-assessment tool as a pilot phase to their initiative.¹⁵⁶

FDA Negotiation with OCR

In negotiating an MOU with OCR, the Food and Drug Administration is currently uncertain about what would be included in the agreement, but expects that the MOU will allow FDA’s Office of Equal Employment and Civil Rights (OEECR) to conduct preliminary onsite inquiries.¹⁵⁷ The FDA wants the MOU to include a guarantee that OCR will provide it with copies of complaints filed involving any of FDA’s funding recipients. Although OEECR refers the complaints it receives to OCR, an FDA complaint may go directly to OCR from one of the FDA district offices or an HHS/OCR regional office. OEECR staff explained that in these instances, they have no way of knowing that a complaint has been filed against one of their grantees. The director of FDA’s OEECR explained that she may have no knowledge of the total number of complaints filed against FDA funding recipients.¹⁵⁸ Indeed, to respond to the Commission’s

questions, OEECR staff had to ask OCR whether any civil rights suits had been filed against the FDA alleging discrimination against minorities or women.¹⁵⁹ The director of OEECR hopes the MOU with OCR will clarify the communication lines on FDA complaints. The deputy director of OEECR also stated that she hopes the MOU will require OCR to inform OEECR when it receives an FDA complaint from an office other than OEECR.¹⁶⁰

Summary

Overall, these instances show that an MOU can have advantages for OPDIVS as well as for OCR. Yet OPDIVS may not even be aware that a tool such as an MOU exists for whatever advantages may be gained. For example, the deputy director of NIH, was not aware that any OPDIV had an MOU with OCR on civil rights enforcement.¹⁶¹ At the same time, the fairly broad language of HCFA’s longstanding MOU may not be the best model. It is unclear whether it delegates a lot or a little responsibility to the OPDIV. The activities that are clearly delegated involve identifying technical assistance needs and providing technical assistance and training for funding recipients. Assistance with preaward reviews, which the HHS Civil Rights Review Team recently proposed, is not mentioned in the HCFA MOU. However, regardless of the language, the HCFA MOU has little impact because it appears that neither HCFA nor OCR is carrying out many of the responsibilities agreed to in the document.

OPDIVS’ Extramural Civil Rights Enforcement Limitations of OPDIV Extramural Involvement

OPDIVS do not have the authority to conduct complaint investigations. When OPDIV staff are approached by recipients to address extramural civil rights compliance requirements, they usually refer that recipient to OCR regional offices.¹⁶² For example, the director of FDA’s Office of Equal Employment and Civil Rights explained every matter that contains the word “discrimination” comes through her office, in-

¹⁵² See *ibid.*

¹⁵³ *Ibid.*

¹⁵⁴ Woods and Martinez letter, May 27, 1998. See OCR Region X Response to Information Request, item H-2-e.

¹⁵⁵ See generally Woods and Martinez letter.

¹⁵⁶ *Ibid.*; OCR Region X Response to Information Request, p. 7.

¹⁵⁷ Lecea and Morales interview, p. 3 (statement of Morales).

¹⁵⁸ *Ibid.*, pp. 6-7 (statement of Lecea).

¹⁵⁹ *Ibid.*, p. 6 (statement of Lecea)

¹⁶⁰ *Ibid.*, pp. 6-7 (statements of Morales and Lecea).

¹⁶¹ NIH entrance conference, p. 1 (statement of Kirschstein).

¹⁶² PSPS interview, p. 8 (statement of Haynes).

cluding most complaints from FDA regional and district offices.¹⁶³ If she receives a complaint, all of the information about it is sent from her office to OCR.¹⁶⁴ However, there are no formal policies or agreements instructing OPDIVS to forward complaints to OCR.¹⁶⁵ Further, OCR staff noted that sometimes OPDIVS handle civil rights complaints and issues on their own, even though they are not authorized to do so.¹⁶⁶

Most OPDIVS also do not conduct preaward reviews or postaward compliance reviews. Further, they do not provide technical assistance on civil rights to program recipients, participants, and beneficiaries.¹⁶⁷ In 1994 some OPDIVS within HHS, including HRSA and NIH, told the Commission that their current role with respect to civil rights compliance, implementation, and enforcement responsibilities was limited to ensuring that grant recipients provide necessary assurances of nondiscrimination before awarding Federal funds.¹⁶⁸ Their agencies do not collect sufficient information from their grant applicants to determine their title VI and title IX compliance status, or conduct followup activities on prospective grantees and actual recipients, such as preaward and postaward desk audits and onsite compliance reviews.¹⁶⁹ It appears that since then OPDIVS have not altered or strengthened their civil rights compliance, implementation, and enforcement efforts.¹⁷⁰ Thus, the OPDIVS' current role with respect to title VI and title IX civil rights compliance, implementa-

tion, and enforcement responsibilities remains limited to ensuring that recipients provide necessary assurances of nondiscrimination (i.e., signed forms) before awarding Federal funds.¹⁷¹

Reviewing Assurance Forms

The OPDIVS are required to ensure that the application packets for Federal financial assistance contain the appropriate civil rights forms.¹⁷² Only a few different application forms were in use among the OPDIVS the Commission studied.¹⁷³ These reflect two different formats.¹⁷⁴ First, the "Application for a Public Health Service Grant, PHS 398" and its parallel form for renewals, "Application for Continuation of a Public Health Service Grant, PHS 2590,"¹⁷⁵ were developed by the NIH and are used for Public Health Service research grants, Research Career Awards, and Institutional National Research Service Awards (training grants).¹⁷⁶ The forms were revised in April 1998 and in addition to being used by NIH have been adopted by the

¹⁶³ Lecea and Morales interview, p. 5 (statement of Lecea).

¹⁶⁴ *Ibid.*

¹⁶⁵ Vada Kyle-Holmes, regional manager, Region VIII, OCR, HHS, telephone interview, Feb. 10, 1999, p. 3.

¹⁶⁶ Ronald Copeland, associate deputy director, Office for Program Operations; Marcella Haynes, director, Policy and Special Projects Staff; and Pamela Malester, deputy director, Quality Assurance and Internal Control Division; OCR, HHS, interview in Washington, DC, July 29, 1998, p. 4 (statements of Haynes and Copeland) (hereafter cited as OCR July 29, 1998 interview).

¹⁶⁷ Ronald Copeland, associate deputy director, Kathleen O'Brien, special assistant to the director; Office for Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13, 1998, pp. 2-3 (statement of Copeland) (hereafter cited as Copeland and O'Brien interview); Kathleen O'Brien, special assistant to director, OCR, HHS, interview in Washington, DC, Nov. 13, 1998, p. 2 (hereafter cited as O'Brien interview).

¹⁶⁸ USCCR, *Federal Title VI Enforcement*, pp. 3, 9, 79, 171, 220, 221.

¹⁶⁹ *See ibid.*, pp. 220-21.

¹⁷⁰ *Ibid.*

¹⁷¹ Copeland and O'Brien interview, p. 2 (statement of Copeland); OPO interview, pp. 15, 25 (statements of Mackey and Shepperd); PSPS interview, pp. 37-39 (statement of Haynes).

¹⁷² *See* table 5.4 for some commonly used grant application forms. OPDIVS also are required to ensure that solicitations for contract projects include appropriate certifications pertaining to civil rights compliance, and that potential contractors submit these certifications as part of their offers. In addition, OPDIVS are required to include in all contracts in excess of \$10,000 a clause requiring the contractor to comply with Executive Order 11246. Finally, as in the case of grants, contract projects involving research with human subjects must meet the requirements of the "NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research." Kirschstein letter, attachment, p. 4.

¹⁷³ The *NIH Grants Policy Statement* lists required application forms for some other programs—"Application for Public Health Service Individual National Research Service Award," PHS-416-1, for fellowships; "Small Business Innovation Research (SBIR) Program Grant Applications," PHS-6246-1 and PHS 6246-2; and "Small Business Technology Transfer (STTR) Program Grant Applications," PHS-6246-3 and PHS 6246-4. *See NIH Grants Policy Statement.*

¹⁷⁴ *See* table 5.4.

¹⁷⁵ HHS, "Application for Continuation of a Public Health Service Grant, PHS 2590" (4/98) (hereafter cited as PHS 2590). *See* NIH, Response to Information Request, tab 11; FDA, Response to Information Request, tab 21.

¹⁷⁶ HHS, "Application for a Public Health Service Grant, PHS 398" (4/98), "foreword," p. 3 (hereafter cited as PHS 398). *See e.g.*, NIH, Response to Information Request, tab 6; FDA, Response to Information Request, tab 6.

Table 5.4
Some Commonly Used Grant Application Forms

Application package	Form no.	Last revision date	Civil rights assurances	Race/Gender of principal investigator/ program director	Gender/ Minority inclusion policy	OPDIVS using this form
Application for a public health service grant	PHS 398	Apr-98	Form(s) (HHS 441, 641, 639-A and 680) or HHS 690	Yes	Yes	NIH, FDA
Application for continuation of a public health service grant*	PHS 2590	Apr-98	Form(s) (HHS 441, 641, 639-A and 680) or HHS 690	No	No	NIH, FDA
Grant application (for use by State and local government applicants and non-governmental applicants for health services projects)	PHS 5161-1	May-96	SF 242B (4/88) Item 6; or 424D (4/88) item 10	No	No	HCFA, HRSA, SAMHSA, CDC, IHS
Application for a public health service grant	PHS 398	May-95	Form(s) (HHS 441, 641, 639-A and 680) or HHS 690	Yes	Yes	AHCPR

* Given that the PHS 2590 is a continuation form, it does not include a complete explanation of the gender and minority inclusion policy that is available in the PHS 398 and in the *NIH Grants Policy Statement*. The PHS 2590 details the reporting requirements in its instructions.

SOURCE: Documents submitted in response to information requests.

FDA.¹⁷⁷ The Administration for Health Care Policy and Research appears to use an older, 1995, version.¹⁷⁸ The second format is PHS 5161-1 "Grant Application," last revised in 1996. This form is for use by State and local government applicants and nongovernmental applicants for health services projects.¹⁷⁹ It was last revised in 1996 and is used by HCFA, HRSA, SAMHSA, and CDC.¹⁸⁰

A civil rights assurance is one of numerous certifications that the applicant's organization must file with the Office for Civil Rights before

the grant application is approved, regardless of which of the two formats is used.¹⁸¹ The instructions for the PHS 398 explain:

Before a grant award can be made a domestic applicant organization must certify that it has filed with the DHHS Office for Civil Rights: an Assurance of Compliance. . .with title VI of the Civil Rights Act of 1964. . . which prohibits discrimination on the basis of race, color, or national origin; section 504 of the Rehabilitation Act of 1973. . . , which prohibits discrimination on the basis of handicaps; title IX of the Education Amendments of 1972 . . . , which prohibits discrimination on the basis of sex; and the Age Discrimination Act of 1975 . . . , which prohibits discrimination on the basis of age.¹⁸²

¹⁷⁷ PHS 398; NIH, Response to Information Request, tab 6; FDA, Response to Information Request, tab 6.

¹⁷⁸ HHS, "Application for a Public Health Service Grant, PHS 398" (5/95) (hereafter cited as PHS 398 (5/95)). See AHCPR, Response to Information Request, tab C.

¹⁷⁹ HHS, "Grant Application, Form PHS-5161-1" (5/96) (hereafter cited as PHS-5161-1).

¹⁸⁰ Ibid. See HCFA, Response to Information Request, "Response to question #4"; HRSA, Response to Information Request, tab 11; SAMHSA, Response to Information Request, tab 16; CDC, Response to Information Request, tab F. HCFA submitted "Application for Federal Assistance" SF424 (Rev. 4-88), which is part of the PHS-5161-1 package. CDC submitted civil rights related excerpts of the PHS-5161-1.

¹⁸¹ For the PHS 398, see p. II, "checklist," "1. Assurances/Certifications" both the form and the sample page; and p. 36, "8. Assurance of Compliance (Civil Rights, Handicapped Individuals, Sex Discrimination, Age Discrimination." For the PHS 5161-1, see SF 424B "Assurances—Non-Construction Programs," item 6, and SF 424D "Assurances—Construction Programs," item 10.

¹⁸² PHS 398, p. 36.

The assurance forms require the signature of an authorized certifying official from the applicant organization attesting that the organization will comply with all Federal statutes relating to non-discrimination and itemize the civil rights laws.¹⁸³ Thus, the applicant organization may not inform its employees, who provide the health care services or conduct health research, of their responsibility to comply with civil rights laws, or hold them accountable for violations of civil rights laws. There is no guarantee to ensure that OCR or the recipient informs individuals of the laws that are applicable to the services they provide.

Apart from the certificate of assurance, applicants for research grants provide some additional information on civil rights issues. First, the PHS 398 package includes a form for personal information on the principal investigator or program director to aid in determining whether the agency is equitably awarding grants to minorities and women.¹⁸⁴ Second, the package includes a policy statement on the inclusion of minorities and women.¹⁸⁵ Third, the application states that "awardees must report annually on enrollment of women and men, and on the race and ethnicity of research participants" when the research involves human subjects.¹⁸⁶

The form with personal information on the principal investigator or program director asks for the age, gender, and the race or ethnic origin that "most closely reflects the [person's] recognition in the community." According to the form, this information is to be used to "monitor the operation of its review and award processes to detect—and deal appropriately with—any instances of real or apparent inequities with respect to age, sex, race or ethnicity of the pro-

posed principal investigator/program director."¹⁸⁷ The personal data is separated from the grant application before the review process so that it does not influence the process of awarding funds.¹⁸⁸ NIH developed the form, but it is unclear whether NIH or any other OPDIVS using the form are routinely analyzing the information on the race, ethnicity, and gender of persons receiving grants.¹⁸⁹

The instructions for the grant application state, "Research involving human subjects must comply with 'NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research'.¹⁹⁰ "Research involving human subjects" is interpreted broadly to include "research involving the collection or study of existing data, documents, records, pathological specimens, diagnostic specimens, or tissues that are individually identifiable."¹⁹¹ The policy is stated as follows:

[W]omen and members of minority groups and their sub-populations must be included in all NIH-supported biomedical and behavioral research projects involving human subjects, unless a clear and compelling rationale and justification establishes inclusion is inappropriate with respect to the health of the subjects or the purpose of the research. Exclusion under other circumstances may be made based on a compelling rationale and justification. Cost is not an acceptable reason for exclusion except when the study would duplicate data from other sources. Women of childbearing potential should not be routinely excluded from participation in clinical research....¹⁹²

Grant applications must develop a research design that addresses the inclusion of women and minorities and proposes outreach programs for recruiting them.¹⁹³ According to the instructions, the scientific and technical merit of the research proposals is evaluated partly with respect to the inclusion of minorities and women.¹⁹⁴

¹⁸³ See, e.g., Standard Form (SF) 424B, "Assurances—Non-Construction Program" and SF 424D, "Assurances—Construction Programs," which are part of the PHS 5161-1 package. The PHS 398 has included separate forms for civil rights laws in the past, i.e., forms HHS 441 for title VI, HHS 641 for handicapped individuals, HHS 649-A for sex discrimination and HHS 680 for age discrimination. Now, a form HHS 690 includes all of these assurances and may be used instead of the four separate forms. See PHS 398, p. II. An even more detailed justification of the civil rights assurance forms is given in the *PHS Grants Policy Statement*, pp. 4-2 and 4-3.

¹⁸⁴ PHS 398, p. KK, "Personal Data on Principal Investigator/Program Director."

¹⁸⁵ *Ibid.*, pp. 28-30.

¹⁸⁶ *Ibid.*, p. 29.

¹⁸⁷ *Ibid.*, p. KK.

¹⁸⁸ *Ibid.*

¹⁸⁹ NIH entrance conference (statement of Jaegar); Lecea and Morales interview, p. 4.

¹⁹⁰ PHS 398, p. 28.

¹⁹¹ *Ibid.*, p. 29.

¹⁹² *Ibid.*

¹⁹³ *Ibid.*

¹⁹⁴ *Ibid.*

Finally, the application instructions state that grantees must report annual enrollment of women and men and the race and ethnicity of research participants.¹⁹⁵ It is unclear whether the reports are used to review compliance of individual grantees.¹⁹⁶ And information on race/ethnicity and gender of either principal investigators/program directors or study participants appears to be required only for research grants and awards.

If OPDIV staff receive an application form with the applicant's standard assurance of compliance, they submit the assurance to OCR for its review and potential followup activities with the grant applicant.¹⁹⁷ OCR staff state that the OPDIV staff are not authorized to do any civil rights related followup activities.¹⁹⁸ Therefore, OPDIV staff assume OCR will do any followup activities after the assurance of compliance has been received.¹⁹⁹ Because the preaward review is OCR's responsibility, OPDIV staff also do not: (a) request applicants' data on the racial/ethnic and gender characteristics of the population eligible to be served, (b) examine prospective recipients' record with respect to compliance reviews conducted during previous years, or (c) obtain information on whether applicants have been found in noncompliance with civil rights laws in recent years.²⁰⁰ Similarly, during the postaward stage, when the OPDIV's program staff conduct site visits to determine the progress of recipients

in carrying out their health-related missions, they would not be expected to investigate the extent to which recipients are complying with civil rights statutes or to investigate complaints of discrimination.²⁰¹

The Civil Rights Review Team recommended that OPDIVS collect information on the applicant's current or past performance with respect to civil rights compliance along with the civil rights assurance form.²⁰² Furthermore, forms that could be used as a self-audit currently exist and might be adapted to be part of the funding application. For example, OCR is currently pilot testing an automated pregrant review data request for HCFA's medicare program.²⁰³

OCR does not expect OPDIV staff to be civil rights investigators but to be aware of statutes such as title VI and refer suspected violations to OCR (most of which are reported to regional offices).²⁰⁴ OCR attempts to educate OPDIV staff about civil rights enforcement (without imposing civil rights compliance and enforcement responsibilities upon them).²⁰⁵ OPDIV staff review civil rights statutes, HHS nondiscrimination policies and procedures, OCR's Web site (which lists frequently asked questions), as well as documents on OCR's guidelines and initiatives, such as OCR's investigative memorandum on title VI prohibition against national origin discrimination, which focused on persons with limited English proficiency.²⁰⁶ OCR also shared the Hill-Burton Compliance Manual with the OPDIVS.²⁰⁷

The role that OCR intends for OPDIVS is limited to ensuring that grant applicants receive

¹⁹⁵ Ibid.

¹⁹⁶ OPDIVS annually tally the aggregate dollars of grants awarded for minority and women's health issues for a departmental report used to monitor the civil rights success of the OPDIVS and Department. Note that such analysis would not reveal questionable civil rights compliance of individual grantees. See Novella Mathews, Office of Budget, Office of the Assistant Secretary of Management and Budget, HHS, fax transmission to Eileen Rudert, Office of Civil Rights Evaluation, USCCR, Mar. 26, 1999 (re: data on minority and women's health).

¹⁹⁷ PSPS interview, p. 37 (statement of Haynes); HHS, OCR, "Assurance of Compliance," Form HHS-690, 5/97.

¹⁹⁸ OPO interview, p. 14 (statement of Nelson), p. 17 (statement of Copeland), and p. 54 (statement of Mackey); PSPS interview, pp. 9, 16, 37 (statement of Haynes); O'Brien interview, p. 2.

¹⁹⁹ PSPS interview, p. 39 (statement of Haynes). HHS OCR regularly conducts compliance reviews of HHS grantee agencies, to determine if such agencies are or are not meeting the civil rights obligations they asserted they were meeting when they signed the assurance. Ibid., p. 39.

²⁰⁰ PSPS interview, p. 37 (statement of Haynes); O'Brien interview, p. 2.

²⁰¹ PSPS interview, pp. 37, 38 (statements of Haynes); O'Brien interview, p. 2.

²⁰² HHS, *Review Team Report*, pp. 24-25.

²⁰³ Ronald G. Copeland, associate deputy director, Office of Program Operations, memorandum to regional managers, Regions I thru X, Aug. 26, 1998 (re: automated pregrant review data request project), pp. 3-4.

²⁰⁴ OPO interview, pp. 15, 18 (statement of Mackey); Copeland and O'Brien interview, p. 3 (statement of Copeland).

²⁰⁵ OCR has not published and disseminated to the OPDIVS any memorandum, guidebook, or manual that specifically explains ways to incorporate civil rights compliance, implementation, and enforcement responsibilities into their agenda and programs to ensure the delivery of services in a nondiscriminatory manner. See PSPS interview, pp. 35-38 (statement of Haynes).

²⁰⁶ PSPS interview, pp. 35, 36 (statement of Haynes); OCR, "Guidance Memorandum on Limited English Proficiency."

²⁰⁷ PSPS interview, p. 35 (statement of Haynes).

the appropriate application forms and submit civil rights assurances. For the most part, that is all OPDIVS are doing. However, some OPDIVS may be moving beyond that limited role. HCFA appears to have taken on more enforcement responsibilities because of its MOU with OCR. HRSA has also assumed more responsibilities, although without an MOU.

Extramural Civil Rights Functions of Specific OPDIVS

HRSA

The Health Resources and Services Administration has an agencywide policy on monitoring civil rights compliance of recipients of Federal assistance²⁰⁸ and conducts a small number of onsite audits. The purpose of HRSA's policy on monitoring civil rights compliance is to describe "policy and procedures for ensuring compliance with applicable civil rights provisions in the conduct of reviewing, awarding, and monitoring HRSA contracts, grants, loans, scholarships, and cooperative agreements."²⁰⁹ The policy lists the applicable civil rights statutes, Executive orders, regulations, and guidelines and tells what Federal agency is responsible for enforcing compliance or implementing guidelines.²¹⁰ It explains HRSA's responsibility for ensuring that the relevant civil rights provisions, materials, and required forms are part of the application packet and for determining that applicants for financial assistance have filed the required assurances of compliance with HHS' Office for Civil Rights.²¹¹ It also states that "HRSA through its offices, Bureaus and the Regional Offices is responsible for the monitoring of its financial assistance recipients Civil Rights compliance status."²¹²

HRSA differs from other OPDIVS in that the agency has taken an aggressive role in monitoring the civil rights compliance of its recipients. HRSA's Office of Equal Opportunity and Civil Rights (OEOCR) carries out this monitoring.²¹³

The policy document outlines five steps to the process. First, based either upon alleged discriminatory practices or random selection, HRSA/OEOCR chooses financial assistance recipients and contractors to review or to receive a site visit. HRSA bureaus and regional offices, with any necessary OEOCR assistance, then collect compliance data for each of the selected recipients and contractors or conduct the site visits. Third, OEOCR analyzes the compliance data and, fourth, issues reports on the civil rights compliance status of the recipients or contractors. Finally, OEOCR provides training and technical assistance for financial assistance recipients and contractors to effect compliance.²¹⁴

HRSA bureaus do site visits and file reports on them with OEOCR.²¹⁵ A "site visit checklist" verifies whether the contracting organization has an affirmative action program that has been updated within the past year and meets statutory requirements or other policies; and whether the contractor has an EEO policy that has been communicated internally with supervisors and through employee training programs, personnel manuals, and company newspapers, magazines, and annual reports.²¹⁶

Data, including information on a recipient's affirmative action plan (if one exists), internal and extramural communications of the EEO policy, and composite work force data, are collected as well as any other available documentation.²¹⁷ The data from all sources provide the opportunity for the OEOCR to develop a profile on the bureau's programs and individual recipient organizations.²¹⁸ Bureau staff are assisted by OEOCR staff when needed for site visits and data collection. OEOCR is responsible for analyzing and interpreting the civil rights data. The data form the basis of the postaward civil rights compliance reports.²¹⁹

According to HRSA circular 92.05, civil rights compliance training is the responsibility of the

²⁰⁸ HRSA circular, no. 92.05. This "HRSA Policy for Monitoring Civil Rights Compliance of Financial Assistance and Acquisition Programs" was distributed to HRSA bureau Directors, the Office of Administration, Bureau Office Directors, and Bureau Division Directors. *Ibid.*

²⁰⁹ *Ibid.*, p. 1.

²¹⁰ *Ibid.*, pp. 1-3.

²¹¹ *Ibid.*

²¹² *Ibid.*

²¹³ *Ibid.*

²¹⁴ *Ibid.*, pp. 4-7.

²¹⁵ *Ibid.*, app. B, pp. 8-9.

²¹⁶ *Ibid.*, pp. 4-7.

²¹⁷ HRSA provided a "checklist" for which the site visitor must obtain information or documents responding to a list of 12 items and six questions about personnel policies and practices. See HRSA, Response to Information Request, tab 2, "Civil Rights Site Visit Checklist," pp. 1-2.

²¹⁸ HRSA circular no. 92.05, p. 5.

²¹⁹ *Ibid.*

OEOCR.²²⁰ This training is designed for all HRSA staff, including headquarters and regional office staff, who have grant and contract responsibilities.²²¹

HRSA's enforcement activities appear to be done without a delegation of authority from HHS/OCR in the form of a memorandum of understanding.²²² Therefore they are not performed under the auspices of a formal understanding between the two agencies. However, it is imperative that OCR work with each OPDIV to ensure a clear, formalized delineation of roles and responsibilities so that HHS agencies knows exactly what their roles are in supporting OCR in its enforcement efforts.²²³

SAMHSA

In September 1998, the Substance Abuse and Mental Health Services Administration Office of Equal Employment Opportunity and Civil Rights (EEOCR) transmitted the guidance from OCR on title VI with respect to persons with limited English proficiency to SAMHSA center directors and program offices.²²⁴ In its directive

²²⁰ Ibid., p. 7.

²²¹ Ibid.

²²² HRSA's response to the Commission's information request stated: "HRSA has not been delegated civil rights responsibilities by the department." Furthermore, asked to provide copies of any cooperative agreements or MOUs, HRSA provided general information on the Hill-Burton Act (e.g., a fact sheet, a pamphlet, reports, and HHS poverty guidelines), but no cooperative agreements or memoranda. See HRSA, Response to Information Request, attachment to cover letter, pp. 1, 3-4 (items 2 and 14) and tab 9.

²²³ In July 1999, HRSA reported that its Office of Equal Opportunity and Civil Rights had already initiated discussions with OCR's Region III regarding a training program to assure that HRSA staff and field personnel are trained to collect civil rights compliance data routinely. See Claude Earl Fox, administrator, Health Resources and Services Administration, letter to Frederick D. Isler, assistant staff director, Office of Civil Rights Evaluation, USCCR, July 1, 1999, p. 3. See also USCCR, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, vol. I, The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999, chap. 4.

²²⁴ Richard Kopanda, acting director, Office of Equal Employment Opportunity and Civil Rights, Substance Abuse and Mental Health Services Administration, HHS, memorandum to center directors, director, OPPC, director, DGM, director, DCM, Sept. 15, 1998 (re: Title VI Prohibition Against National Origin Discrimination Respecting Persons with Limited English Proficiency—Guidance from the Office for Civil Rights) (hereafter cited as SAMHSA, Memorandum

on the guidance, the EEOCR instructed the centers on the requirements of the guidance for health and social service providers, and stated SAMHSA's policy to implement the guidance in the agency's grant contract programs promptly and effectively.²²⁵ The memorandum stated that the agency should incorporate an "appropriate reference to the responsibilities of recipients of SAMHSA financial assistance to persons with LEP. . . ." ²²⁶ This assisted OCR in a major outreach and education campaign it was conducting on its LEP guidance.

HCFA

The Health Care Financing Administration administers the two largest Federal health programs, medicare and medicaid, which are a primary source of health insurance for minorities, and the black population in particular.²²⁷ HCFA's²²⁸ vision for the future is to "guarantee equal access to the best health care" through a commitment that "[a]ll individuals will be given an unconditional assurance of having the same opportunity to have their health care needs met, regardless of location, income, or other circumstances"; and "[t]he quality of health care they receive is the best that can be provided."²²⁹

Policy on Civil Rights. HCFA has had a Civil Rights Compliance Policy Statement since at least 1994 that expresses a commitment to ensuring that there is no discrimination in the de-

to Center Directors on LEP Guidance). See SAMHSA, Response to Information Request, tab 9.

²²⁵ SAMHSA, Memorandum to Center Directors on LEP Guidance.

²²⁶ Ibid.

²²⁷ Medicare and medicaid were established in 1965. Medicare provides health insurance coverage for people 65 and over, younger people receiving social security disability benefits, and persons who need dialysis or kidney transplants for treatment of end-stage kidney disease. The beneficiaries included approximately 33 million senior citizens, 5 million social security disability benefits, and 270,000 kidney disease patients. HHS, Health Care Financing Administration, fact sheet, February 1997, p. 1. See vol. I, chap. 2.

²²⁸ Established in 1977, HCFA's mission is to assure health care security for its beneficiaries. HCFA has defined health care security as access to affordable and quality health services, protection of the rights and dignity of beneficiaries, and provision of clear and useful information to beneficiaries and providers to assist them in making health care decisions. HHS, Health Care Financing Administration, "About HCFA," May 14, 1998, p. 4, accessed at <<http://www.hcfa.gov/about.htm#Whatis>>.

²²⁹ Ibid., p. 5.

livery of health care services under HCFA programs.²³⁰ The most recent version of this statement was distributed in April 1998.²³¹ The HCFA Administrator asked HCFA leadership to share the statement with contractors, State agencies, health care providers, and all others directly involved in the administration of HCFA programs. It states:

The Health Care Financing Administration's vision in the current Strategic Plan guarantees . . . beneficiaries . . . equal access to the best health care. Pivotal to guaranteeing equal access is the integration of compliance with civil rights laws into the fabric of all HCFA program operations and activities. . . . [C]ivil rights laws [applicable to] recipients of HCFA funds . . . include title VI of the Civil Rights Act, as amended, section 504 of the Rehabilitation Act, as amended, . . . and title IX of the Education Amendments of 1972, as well as other related laws. The responsibility for ensuring compliance with these laws is shared by all HCFA operating components. Promoting attention to and ensuring HCFA program compliance with civil rights laws are among my highest priorities for HCFA, its employees, contractors, State agencies, health care providers, and all other partners directly involved in the administration of HCFA programs.²³²

The HCFA Civil Rights Statement also says, "To achieve its civil rights goals, HCFA will continue to incorporate civil rights concerns into the culture of our agency and its programs."²³³

²³⁰ See Bruce C. Vladeck, administrator, Health Care Financing Administration, HHS, memorandum to HCFA leadership, Oct. 20, 1994 (re: HCFA Civil Rights Compliance Policy Statement) (hereafter cited as HCFA, 1994 Civil Rights Compliance Statement). See HCFA, Response to Information Request, "Response to question #7." The language of the 1994 version was similar to the 1998 statement but tended to emphasize enforcement rather than compliance with civil rights laws and focused just on title VI. See also HCFA, 1998 Civil Rights Compliance Statement.

²³¹ HCFA, 1998 Civil Rights Compliance Statement.

²³² *Ibid.*

²³³ *Ibid.* Three of HCFA's 10 regional offices submitted copies of the Compliance Policy Statement that had been sent to their funding recipients, suggesting that only one-third of the HCFA regional offices demonstrated awareness of the formal civil rights policy of their own OPDIV. See Gary A. Bailey, director, Health Plan Purchasing and Administration, Region VI, Health Care Financing Administration, HHS, memorandum to section 1876 contractors and Medicare+ Choice Pending, Dec. 16, 1998 (re: Health Care Financing Administration Civil Rights Compliance Policy Statement); Alex E. Trujillo, acting regional administrator, Region VIII, Health Care Financing Administration, HHS, Medicare Regional Information letter to All Part A Intermediaries [and] All Part B Carriers,

Efforts to Improve Data Collection on Medicare Beneficiaries. Because medicaid is a Federal-State program, HCFA determined that it would be difficult to require that a State make changes to the race/ethnicity field in its data system for that program.²³⁴ Consequently, HCFA focused its upgrading of race/ethnicity data on its medicare enrollment database.²³⁵ According to HCFA's senior advisor for technology to the chief information officer, the data in HCFA's medicare files are used for medical and sociological research, insurance projections, and detection of fraud or discrimination; and beneficiaries' race/ethnicity is a key variable in any of these efforts.²³⁶ Although HCFA acknowledges that inadequate access or care can be due to reasons other than discrimination, HCFA staff use medicare claims with associated patient racial/ethnic data to determine if members of minority groups receive different types or levels of health care than nonminority individuals.²³⁷

In 1995 the racial/ethnic status of approximately 1.43 million (or 3.8 percent) of the 37.5 million medicare beneficiaries was identified in

June 3, 1998 (re: HCFA Civil Rights Compliance Policy Statement); Elizabeth Foley, director, Health Plan and Provider Operations, Region IX, Health Care Financing Administration, HHS, "Regional Office HMO/CMP Letter 98-12," July 10, 1998 (re: HCFA Civil Rights Compliance Policy Statement). See also HCFA, Response to Information Request, "Region VI," "Region VIII," "Region IX." However, according to the deputy administrator of HCFA, all of the regional offices and central office components were given the HCFA Civil Rights Compliance Policy Statement for distribution. Letters expressing the HCFA administrator's commitment to civil rights and the responsibilities of recipients of Federal funds were sent to all medicare contractors in June 1998 and to all State medicaid directors in August 1998. Similar letters also were sent to those who operated health maintenance organizations. On Dec. 3, 1998, the director of OEOCR sent a letter to HCFA contractors advising them of HCFA's civil rights and sexual harassment policies. Hash letter, attachment, p. 2.

²³⁴ Steve Melov, director, Management Information and Analysis Division, and Pamela Malester, deputy director, Quality Assurance and Control Division, Office of Management Planning and Evaluation, OCR, HHS, interview in Washington, DC, Nov. 20, 1998, p. 10 (statement of Melov) (hereafter cited as OMPE interview).

²³⁵ *Ibid.*, p. 10 (statement of Melov); John Van Walker, senior advisor for technology to the chief information officer, Office of Information Services, Health Care Financing Administration, HHS, telephone interview, Dec. 30, 1998, pp. 1-3 (hereafter cited as Van Walker interview).

²³⁶ Van Walker interview, p. 2.

²³⁷ *Ibid.*

HCFA's database as "other" or "unknown."²³⁸ HCFA tracks additional information on beneficiaries, such as name, address, date of birth, and dates of medicare entitlement, to determine recipients' eligibility for services and actual treatments received.²³⁹ Because of HCFA's responsibility to monitor health care access and service delivery for potential discrimination against various groups, HCFA was concerned about not having definitive information on the racial/ethnic composition of its medicare population.²⁴⁰ In response to the litigation that sought to have HCFA collect race/ethnicity data on every claim, as well as HCFA's concern about the deficiencies in its database holdings with respect to classifying medicare beneficiaries' race/ethnicity, HCFA decided to improve the information in the race/ethnicity field of its medicare enrollment database and decrease the number of individuals classified as "other" or "unknown."²⁴¹

Between November 1995 and July 1996, HCFA mailed surveys to 2.1 million beneficiaries listed in its medicare database with race/ethnicity categories of "other" or "unknown" and beneficiaries who had surnames that met census criteria for Hispanic, many of whom were potentially misclassified as either white or black.²⁴² The survey asked recipients to identify their racial/ethnic status, choosing from the categories white, not of Hispanic origin; black, not of Hispanic origin; Hispanic; American Indian or Alaskan Native; and Asian or Pacific Islander.²⁴³ Survey recipients were informed that complying with HCFA's request was voluntary, and that the information obtained from the instrument could potentially ensure that medicare beneficiaries have access to medical facilities and receive high-quality care without regard to their race/ethnicity.²⁴⁴ As a result of this survey, HCFA was able to identify the correct racial/ethnic status of 356,000 Hispanics, 208,000

²³⁸ Ibid. The medicare database classifies recipients as "unknown" if they did not divulge their racial/ethnic status when they enrolled in medicare. Ibid., pp. 1-2.

²³⁹ Ibid., p. 2.

²⁴⁰ Ibid.

²⁴¹ Ibid.

²⁴² Ibid.

²⁴³ Ibid.; Questionnaire: Race/Ethnic Description, OMB no. 0938-0674.

²⁴⁴ Van Walker interview, p. 2.

Asians or Pacific Islanders, and 20,000 American Indians or Alaskan Natives, thus decreasing the percentage of recipients identified as "unknown" or "other" to 2.4 percent (down from 3.8 percent in 1995).²⁴⁵

Promotion of Civil Rights Compliance in Grants and Contracts. HCFA disseminates information about funding availability through its *Grants Administration Manual*, which gives explicit instructions for widely disseminating information about funding availability and for soliciting applications from minority- and woman-owned businesses. "[T]o promote the widest possible dissemination of information to all potential applicants concerning grant programs," the manual recommends *Federal Register* announcements, targeted mailings, and alternate sources such as magazines, newspapers, and the Internet.²⁴⁶

HCFA's *Grants Administration Manual* states that HHS policy is "to afford small, minority and woman-owned businesses the maximum opportunity, consistent with law, to participate in the Department's financial assistance programs."²⁴⁷ To promote this policy, a small business program manager maintains a list of small, minority, and woman-owned businesses that may be interested in participating in assistance programs, and mails information packets directly to them. The mailing list has names of eligible businesses that have asked to be placed on the list or have bid upon previous grants or contracts; Web site addresses where small businesses advertise to Federal and State agencies; local and national business directories; and referrals from within HHS.²⁴⁸ All applications under programs for which for-profit organizations are eligible to apply include certifications for minority business enterprises and woman-owned businesses, so that applicants can designate the special consideration they wish to receive.²⁴⁹

Once a grant is approved, HCFA has a grants management system in place to ensure program compliance with Federal laws, regulations, and

²⁴⁵ Ibid., p. 3.

²⁴⁶ HCFA transmittal 97.04 (12/23/97), *HCFA Grants Administration Manual*, GAM Section 2.03.203, "2.03.203-3 Promoting Widespread Dissemination of Funding Availability," Part A, "Methods of Dissemination," p. 1.

²⁴⁷ Ibid., "2.03.203-5 Soliciting Applications from Small, Minority, and Women-Owned Businesses," p. 5.

²⁴⁸ Ibid., Section B, "Application Certifications," pp. 6-7.

²⁴⁹ Ibid., Section A, "Procedures," pp. 5-6.

policies; however, compliance with civil rights laws is not an explicit part of it. HCFA appoints a program official and a grant management official to each grant. The program official serves as a project officer and is concerned with programmatic, scientific, and/or technical aspects of the grant.²⁵⁰ Grants management officers provide expertise in business and other nonprogrammatic areas of grants administration, and ensure that the grantee fulfills requirements of laws, regulations, and administrative policies.²⁵¹ The program management and grants management functions are kept separate. For example, grants management officers do not report to an official who exercises program management authorities (including approval of grant applications).²⁵²

Another staff person involved in grants management is the grants policy officer. This position has oversight of grants operations, issues policies, and conducts technical assistance and provides training for HCFA staff and grantee organizations.²⁵³ According to HCFA's *Grants Administration Manual*, the grants policy officer should conduct onsite compliance reviews of grantee organizations and should conduct studies "to determine the need for changes in policies or to develop and test innovative policies and procedures."²⁵⁴ The grants policy officer is also responsible for providing training on grants management policies to both grants management staff and program staff.²⁵⁵ Notably, collecting information about the number or percentage of minorities and women who are employed or served by grantee organizations is not a stated responsibility of either the grants manager officer or the grants policy officer.

Outreach. HCFA has developed a manual titled *Outreach Standards* that provides guidance for producing outreach materials. The manual covers topics such as "cultural competence civil

rights," "approved anti-discrimination language" and "writing for low-literate audiences."²⁵⁶ This guidance states:

Language, images and illustrations used in publication must represent our diverse beneficiary populations with respect to race, color, age, sex, . . . and national origin. Sometimes, this may mean that separate ethnic or cultural versions of a basic test may be required. Content and style shall not reflect adversely on any group or groups of people who might be identified in fact or by implication. . . . Where space permits materials should include information on federal anti-discrimination provisions.²⁵⁷

The guidance gives standard language about discrimination to be included in publications in a short form for leaflets and small publications, and in a longer form for major publications such as a handbook or guide.

The guidance on writing discusses low literacy, cultural differences, and cultural sensitivities. It recommends clear and simple writing for everyone and notes that 40 percent of the minority population reads below a 6th grade level.²⁵⁸ It gives a chart for determining readability of materials from the number of sentences and syllables per 100 words.²⁵⁹ The guidance also gives several steps for writing for a low-literacy reader. The guide does not make any suggestions for outreach to persons for whom English is a second language, for example, whether bilingual materials should be provided, or whether an interpreter should be available.

FDA OEECR

FDA affects the inclusion of minorities and women in research though its required approvals for the use of drugs and medical devices, and the Office of Equal Employment and Civil Rights (OEECR) has a role in this process. An interagency committee reviews and analyzes agency and other medical research protocols for the participation of minorities before drugs and medical

²⁵⁰ HCFA transmittal 97.01 (02/12/97), HCFA *Grants Administration Manual*, GAM Section 1.04.204, "1.04.204-3 Appointment of Discretionary Grants Managers and Program Officials," Part C, "Program Officials," p. 3.

²⁵¹ *Ibid.*, Part B, "Grants Management Officers," p. 2.

²⁵² *Ibid.*, "1.04.204-4 Separation of Discretionary Grants Organizational and Operational Functions," Part A, "Independence of Grants Management Officers," p. 3.

²⁵³ *Ibid.*, "1.04.204-7 Discretionary Grants Policy Officer Functions," p. 10.

²⁵⁴ *Ibid.*, Part E, "Perform or Manage On-Site Reviews," p. 10.

²⁵⁵ *Ibid.*, Part F, "Provide Training," p. 11.

²⁵⁶ HHS, Health Care Financing Administration, *Outreach Standards*, transmitted July 7, 1998 (hereafter cited as HCFA, *Outreach Standards*), "Printed Materials," "Cultural Competence Civil Rights." See HCFA, Response to Information Request, "Response to question #6."

²⁵⁷ HCFA, *Outreach Standards*, "Standard Language for Anti-discrimination."

²⁵⁸ *Ibid.*, "Writing for Low-literate Readers."

²⁵⁹ *Ibid.*, "Determining Readability, Fry Readability Graph: Directions for Use."

devices are approved for widespread use in the United States. If the drug or medical device has not been tested on diverse populations, FDA can deny approval, which would prohibit use of the drug or medical device in this country.

One OEECR staff member has been assigned to participate on the committee. The staff person attends committee meetings that are held about once a month, reviews research protocols, and identifies civil rights issues.²⁶⁰ The staff member reports committee discussions to the OEECR deputy director.²⁶¹ By serving on such a committee, OEECR staff have the opportunity to add the civil rights perspective.²⁶² The staff should be able to point out to the scientists and the principal investigators on the committee those points or issues that may not be understood by the general population. The deputy director of OEECR thinks there is a role for OEECR in the process, in providing civil rights information and perspective, and the support for the participation of women and minorities in clinical trials.²⁶³

FDA As a Conduit for Collecting Extramural Civil Rights Complaints. The director of OEECR said that the Department has not given OEECR any enforcement authority.²⁶⁴ OEECR does not do any title VI or title IX enforcement and compliance activities and would have to negotiate with the Department to receive enforcement authority.²⁶⁵ OEECR staff do not review grants, conduct preaward or onsite activities, handle or make decisions about complaints, collect racial/ethnic data, investigate complaints, or review assurance forms for compliance.²⁶⁶ OEECR is merely a conduit for collecting extramural complaints that come to FDA and sending them to HHS' OCR for appropriate disposition or determination.²⁶⁷ However, OEECR may have a broader civil rights role in the future as it was in the process of developing a memorandum of understanding with OCR that was scheduled to be completed by June 15, 1999.²⁶⁸

²⁶⁰ Leeca and Morales interview, p. 2. (statement of Leeca).

²⁶¹ Ibid.

²⁶² Ibid., p. 4 (statement of Morales).

²⁶³ Ibid.

²⁶⁴ Ibid., p. 5.

²⁶⁵ Ibid.

²⁶⁶ Ibid. (statement of Leeca).

²⁶⁷ Ibid.

²⁶⁸ Ibid., p. 2.

OCR Authority for Civil Rights Enforcement in Block Grants

With respect to block grant programs, OCR has no line authority²⁶⁹ over the activities of OPDIVS;²⁷⁰ the OPDIVS' civil rights compliance, implementation, and enforcement duties are not directly guided and monitored by OCR.²⁷¹ Consequently, HHS agencies that sponsor State-administered block grant programs, such as HRSA or SAMHSA, could have difficulty providing comprehensive guidance to State recipients on their own compliance responsibilities, their efforts to ensure the subrecipients' compliance, and their efforts to develop methods of administration.²⁷² In addition, OPDIVS also may have difficulty ensuring that States comply with civil rights requirements and sufficiently assess, monitor, and enforce subrecipients' compliance activities.²⁷³

For instance, although HHS requires its State recipients to submit methods of administration (specifying their procedures and activities for evaluating, maintaining, achieving, and ensuring their own compliance with title VI and monitoring and enforcing subrecipients compliance activities²⁷⁴), the OPDIVS do not provide State agencies guidance in completing this document, nor do they review the submitted methods or monitor States' adherence to such

²⁶⁹ "Line authority" refers to an agency's (such as OCR) oversight of the activities (those that are related to and not related to civil rights enforcement matters) performed by a particular entity (such as an HHS OPDIV). See Copeland and O'Brien interview, p. 4 (statement of Copeland).

²⁷⁰ USCCR, *Federal Title VI Enforcement*, pp. 220, 221; Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy associate director, Office of Programs Operations, OCR, HHS, interview in Washington, DC, Oct. 16, 1998, p. 8 (statement of O'Brien and Mackey) (hereafter cited as O'Brien and Mackey interview); OPO interview, pp. 16, 26 (statements of Mackey); Copeland and O'Brien interview, p. 4 (statement of Copeland); O'Brien interview, pp. 1-2.

²⁷¹ USCCR, *Federal Title VI Enforcement*, pp. 220, 221, 239; OPO interview, pp. 16, 26 (statements of Mackey); O'Brien interview, pp. 1-2.

²⁷² USCCR, *Federal Title VI Enforcement*, pp. 9, 232. Methods of administration are procedures and activities detailing the States' strategies to ensure their compliance with civil rights laws and oversee, assess, ensure, and enforce their subrecipients' compliance. See *ibid.*, pp. 178-79.

²⁷³ *Ibid.*, pp. 2-3, 78-79, 178. See vol. II, chap. 4, for a discussion of HHS block grants.

²⁷⁴ USCCR, *Federal Title VI Enforcement*, pp. 9, 178-79. See also 28 CFR § 42.410 (1998); 45 CFR § 80.4(b)(2) (1998).

procedures.²⁷⁵ Further, OPDIVS that administer block grant programs are not authorized, or required, to evaluate States' and subrecipients' compliance with civil rights statutes and regulations.²⁷⁶

OCR's Leadership Role over OPDIVS

According to OCR staff, OCR was established in the 1960s to be a separate entity from all HHS program operations (i.e., OPDIVS) and headquarters divisions, in order to "watch over everybody," implement and enforce civil rights objectives, and ensure that all HHS programs operate in a nondiscriminatory manner.²⁷⁷ With respect to OPDIVS, OCR "provides leadership and guidance in planning and implementing civil rights compliance activities"; "plans and conducts a continuing program of evaluating civil rights compliance activities"; and "conducts [a] program of training for [OPDIV] staff to carry out their civil rights responsibilities."²⁷⁸ OCR staff stated that none of the Department's OPDIVS had been delegated any authority to enforce title VI or any other civil rights statute.²⁷⁹

Departmental Guidance on OCR's Role

The Secretary's delegation of authority for civil rights enforcement to OCR makes clear that OCR, not the OPDIVS, is responsible for civil

rights enforcement, including complaints investigations and compliance reviews.²⁸⁰ At the same time, the OPDIVS have a role in compliance activities, but presumably only under OCR leadership and guidance and according to training OCR has provided. Thus, civil rights enforcement among the OPDIVS largely depends on how OCR and the OPDIVS work together to implement and enforce civil rights laws.

A 1993 departmental report by the Civil Rights Review Team recognized both the lack of a relationship between OCR and the OPDIVS and the importance of such a relationship for enforcing civil rights.²⁸¹ The Civil Rights Review Team was created to examine the mission and function of OCR and make recommendations for strengthening the office. The team concluded that OCR's review activities were not integrated in a meaningful way into the program management functions of the OPDIVS.²⁸² OCR had "only minimal ongoing liaison" with the OPDIVS.²⁸³ The Civil Rights Review Team argued that this lack of coordination between OPDIVS and OCR causes OCR to be reactive.²⁸⁴ Staff in OPDIVS who assume civil rights compliance responsibilities (e.g., reviewing applicants' statements of assurance) are not managed by and do not report directly to OCR's director.²⁸⁵ Although the director of OCR guides HHS' enforcement activities related to title VI, OCR does not have a formal oversight and monitoring system to review, evaluate, and direct the performance of OPDIVS as it relates to civil rights compliance activities.²⁸⁶ Instead, guidance to the OPDIVS tends to be informal.²⁸⁷

The Civil Rights Review Team's report explained that "protecting the rights of citizens to access and fair treatment in HHS programs" is a responsibility that must be shared by all HHS operating and headquarters divisions, and that

²⁷⁵ USCCR, *Federal Title VI Enforcement*, pp. 9, 232; Copeland and O'Brien interview, p. 3 (statement of Copeland); Gary Carpenter, public health analyst, Health Resources and Services Administration, HHS, Sept. 18, 1998, interview, pp. 4-5 (hereafter cited as Carpenter interview); Marilyn Stone, branch chief, Grants Policy Branch, Grants and Procurement Management Division, Health Resources and Services Administration, HHS, Sept. 17, 1998, interview, pp. 1-2 (hereafter cited as Stone interview). Discussion of OPDIVS' extent of examination of State grantees' "methods of administration" is addressed in vol. II, chap. 4.

²⁷⁶ See Carpenter interview; Stone interview; USCCR, *Federal Title VI Enforcement*, pp. 3, 9, 77-80, 88-149, 178-80, 232-46; Copeland and O'Brien interview, p. 3 (statement of Copeland).

²⁷⁷ OPO interview, pp. 26, 28 (statement of Mackey).

²⁷⁸ 47 Fed. Reg. 20,032-35 (1982).

²⁷⁹ The associate deputy director of HHS OCR's Office of Program Operations (OPO), the director of OPO's Division of Voluntary Compliance and Outreach, the director of HHS' Policy and Special Projects Staff, the deputy to OCR's deputy director, and OCR's special assistant agreed with this statement. See OPO interview, p. 14 (statement of Nelson), p. 17 (statement of Copeland), and p. 54 (statement of Mackey); PSPS interview, pp. 7, 8, 9, 16, 37-39 (statement of Haynes); O'Brien interview, p. 2.

²⁸⁰ 47 Fed. Reg. 20,032-35 (1982).

²⁸¹ See generally HHS, *Review Team Report*, p. 2.

²⁸² *Ibid.*

²⁸³ *Ibid.*, p. 9.

²⁸⁴ *Ibid.*, p. 24.

²⁸⁵ O'Brien and Mackey interview, p. 8 (statement of O'Brien and Mackey); OPO interview, pp. 16, 26 (statement of Mackey); O'Brien interview, pp. 1-2. See also USCCR, *Federal Title VI Enforcement*, pp. 220-21.

²⁸⁶ *Ibid.*

²⁸⁷ O'Brien and Mackey interview, p. 8 (statement of O'Brien and Mackey).

civil rights functions should also be shared.²⁸⁸ The team's report implicitly distinguished two types of civil rights functions that should be shared between OCR and the OPDIVS. The first is "traditional enforcement of civil rights statutes," which has "focused on detecting and stopping discrimination practiced by an employee or institution against protected individuals or classes of individuals who may have been denied access or appropriate services."²⁸⁹ This type of activity involves complaints investigations, compliance reviews, and the assurances of compliance that OPDIVS obtain from their grantees. But, the report urged HHS to move beyond traditional enforcement of civil rights statutes to deal with broader civil rights issues.²⁹⁰ This second function involves identifying discriminatory practices or systemic discrimination, such as whether health and human services programs are designed or operated in such a manner as to have a discriminatory effect,²⁹¹ and implementing departmentwide approaches with a minimum of processing steps for prevention or resolution of problems.²⁹²

The Civil Rights Review Team did not suggest major changes in the roles of OCR or the OPDIVS with respect to traditional civil rights enforcement. The report recognized that 75 percent of OCR resources were devoted to complaints handling and merely recommended that this process be made to work faster and more efficiently to allow more time for other civil rights activities.²⁹³ It also acknowledged that OCR could not "monitor the civil rights performance of the more than 100,000 organizations which receive HHS funding," largely through the OPDIVS.²⁹⁴ OCR has been overburdened doing precertification reviews of just the medicare programs under the HCFA.²⁹⁵ The civil rights compliance of grantees has mostly been promoted by the OPDIVS, which require grant applicants to file a signed assurance form that they will com-

ply with Federal civil rights obligations.²⁹⁶ The review team's report suggested that OPDIVS obtain detailed information on grant applicants' past performance with respect to civil rights (termed "a self-audit") in addition to the signed assurance of compliance.²⁹⁷ OCR could then do a sampling of compliance reviews or audits of the OPDIVS' grantees.²⁹⁸

Apart from the OPDIVS' added responsibility of collecting self-audits from grant applicants, the Civil Rights Review Team's recommendations did not preclude them from doing traditional civil rights enforcement, stating that "[i]nsofar as [OPDIVS] may agree and be able," they may perform compliance reviews or engage in "other compliance or early complaint resolution activities,"²⁹⁹ although only under a negotiated MOU with OCR.³⁰⁰ The team suggested several ways in which OCR could involve the OPDIVS in traditional civil rights enforcement. OCR could use the OPDIVS as an initial and ongoing avenue for providing civil rights guidance and information to recipients. It could use the OPDIVS to carry out pregrant reviews of the recipients' self-audits, to gather information for OCR reviews, and to audit activities in the course of monitoring civil rights compliance. OCR could notify OPDIVS of complaints filed against grantees and the final findings and solicit their help in identifying problematic trends. It could use the OPDIVS for early intervention to resolve complaints.³⁰¹

With respect to the broader efforts to identify discriminatory practices, the Civil Rights Review Team recommended collaboration of OCR and OPDIV experts in which OCR could raise focused issues and involve OPDIVS and their program experts in identifying strategies to address them.³⁰² According to the review team report, each OPDIV should have a designated civil rights advisor to act as liaison with OCR.³⁰³

²⁸⁸ HHS, *Review Team Report*, pp. 2, 4, 22.

²⁸⁹ *Ibid.*, p. 13.

²⁹⁰ *Ibid.*

²⁹¹ *Ibid.*

²⁹² *Ibid.*, pp. 4, 22-23.

²⁹³ *Ibid.*, p. 21.

²⁹⁴ *Ibid.*, p. 22.

²⁹⁵ *Ibid.*, pp. 23-24.

²⁹⁶ *Ibid.*, p. 23.

²⁹⁷ *Ibid.*, pp. 24-25.

²⁹⁸ *Ibid.*

²⁹⁹ *Ibid.*, pp. 23-24.

³⁰⁰ *Ibid.*, p. 23.

³⁰¹ *Ibid.*, p. 24.

³⁰² *Ibid.*, pp. 2, 12-13, 15.

³⁰³ *Ibid.*, p. 24.

OCR Strategic Plan

In December 1994, more than a year after the Civil Rights Review Team issued its report, OCR released a newly developed strategic plan.³⁰⁴ The plan responded to many of the concerns of the Civil Rights Review Team. For example, in developing its strategic plan, OCR consulted with the OPDIVS³⁰⁵ to develop program priorities that address the most acute problems of discrimination,³⁰⁶ as the review team's report recommended.³⁰⁷ The director of OCR indicated that OCR planned to work in conjunction with the OPDIVS in a number of title VI enforcement areas, including policy development and monitoring State recipients.³⁰⁸ OCR also planned to "seek innovative means for expanding partnerships for civil rights awareness and implementation throughout the Department's programs" and to "integrate civil rights into the ongoing operations and oversight of all HHS programs."³⁰⁹

On enforcement activities, the strategic plan demonstrated an intention to increase OPDIV awareness of civil rights compliance matters by training managers and staffs.³¹⁰ On broader civil rights issues and policies, the strategic plan mentioned an OCR intention to propose to the HHS Secretary a Secretarial delegation of authority instructing OCR to work with the OPDIVS to ensure that HHS-sponsored programs do not discriminate on the basis of race, color, or national origin.³¹¹ OCR also planned to interact more with OPDIVS on issues related to developing civil rights guidelines, customer out-

reach, and data collection, and to ensure that civil rights considerations were incorporated into HHS programs and policies.³¹²

The strategic plan also mentioned an OCR goal to increase the number of program reviews that OPDIVS do incorporating civil rights.³¹³ However, this does not refer to compliance reviews of funding recipients, but to review of OPDIV policies, guidance, and provisions for broader program accessibility.³¹⁴ To conduct more investigations and reviews of funding recipients, the plan suggests that OCR identify and establish cooperative agreements with State agencies. The OPDIVS will help identify the State agencies. The State agencies would conduct postgrant reviews of compliance that are limited in scope and subject to OCR review.³¹⁵

The strategic plan does not make any mention of OPDIV involvement in preaward reviews, as the Civil Rights Review Team recommended. The review team's suggested pilot program was to have OPDIVS mail pregrant certification and technical assistance packages.³¹⁶ Another suggestion was to prepare a compliance guidebook to assist OPDIVS in performing a structured set of activities.³¹⁷ It is not clear from either of these suggestions whether the intent is for OPDIVS to conduct preaward reviews.

Finally, the strategic plan includes a long-term strategy of establishing "an ongoing notification process" to inform OPDIVS of OCR's "initiation of high impact case work and other civil rights matters."³¹⁸ Increasing numbers of OPDIV program officials are expected to be routinely informed of the results of OCR's investigative and outreach initiatives.³¹⁹ However, it is unclear whether this strategy will address the concerns of OPDIVS that do not always know when their funding recipients and providers are the subject of a complaint or a compliance review.³²⁰

³⁰⁴ HHS, OCR, "Strategic Plan," Dec. 16, 1994 (hereafter cited as OCR "Strategic Plan, 1994"). See vol. II, chap. 3.

³⁰⁵ USCCR, *Federal Title VI Enforcement*, p. 221, note 29.

³⁰⁶ Dennis Hayashi, director, OCR, HHS, letter to Frederick D. Isler, acting assistant staff director, Office of Civil Rights Evaluation, USCCR, Nov. 4, 1994, enclosure, "Title VI Plans—Department of Health and Human Services," p. 2 (hereafter cited as Hayashi letter). Other headquarters staff confirmed that the OPDIVS' assistance was solicited when the plan was developed. Staff agreeing with this included the Secretary, the OCR director's special assistant, and the director of OCR's Policy and Special Projects Staff. See USCCR, *Federal Title VI Enforcement*, p. 221; Copeland and O'Brien interview, p. 4 (statement of O'Brien); PSPS interview, p. 40 (statement of Haynes). See also OCR "Strategic Plan, 1994," p. 3.

³⁰⁷ HHS, *Review Team Report*, p. 15.

³⁰⁸ See Hayashi letter.

³⁰⁹ *Ibid.*, pp. 1–2.

³¹⁰ OCR "Strategic Plan, 1994," p. 9.

³¹¹ *Ibid.*, pp. 7–8.

³¹² *Ibid.*, pp. 8, 12–13, 15–16.

³¹³ *Ibid.*, p. 9.

³¹⁴ *Ibid.*, pp. 7–9.

³¹⁵ *Ibid.*, pp. 16–17.

³¹⁶ *Ibid.*, p. 17.

³¹⁷ *Ibid.*

³¹⁸ *Ibid.*, p. 10.

³¹⁹ *Ibid.*

³²⁰ See, e.g., Lecea and Morales interview, p. 6.

OCR's Coordinated Activities with OPDIVS

In 1998 OCR staff stated that working more closely with the OPDIVS was one of OCR's major goals.³²¹ According to OCR's director of Policy and Special Projects Staff, the interaction between OCR and OPDIVS³²² has become a regular, positive activity, and serves to ensure that HHS programs are reaching the individuals whom the programs are intended to serve and meeting the needs of HHS' constituency.³²³

OCR identified various ways in which the office works with OPDIVS. OCR works with OPDIVS to ensure they understand their compliance responsibilities for title VI and other civil rights laws.³²⁴ They also work together to develop policies, civil rights guidelines, indicators of broader access for protected groups, and standards for determining adverse impact,³²⁵ and they sometimes jointly review adoption and foster care agencies and programs such as Temporary Assistance to Needy Families (TANF).³²⁶

OCR and Specific OPDIVS

FDA

FDA's Office of Equal Employment and Civil Rights (OEECR) staff person assigned to work with OCR reported very little communication with OCR in the past. She stated that OEECR was "left out in the cold about extramural civil rights."³²⁷ Since OEECR initiated the effort to develop an MOU, the communication between the two offices has improved.³²⁸ Yet, apart from interaction concerning the MOU, FDA staff did not describe a close relationship with OCR. FDA's OEECR did receive OCR's guidance on limited English proficiency and a briefing on the document.³²⁹ In general, OEECR has received only minimal technical assistance and guidance

³²¹ OCR, July 29, 1998, interview, p. 3.

³²² PSPS interview, pp. 34-35 (statement of Haynes).

³²³ *Ibid.*, pp. 15, 34, 35 (statement of Haynes).

³²⁴ *Ibid.*, pp. 6, 38 (statements of Haynes).

³²⁵ *Ibid.*, p. 40 (statement of Haynes). OCR's director of PSPS mentioned Healthy People 2000 and OCR's "Dog Guide Policy" (use and availability of dog guides to assist individuals going to hospital clinics or other health care facilities) as examples of OCR/OPDIV interaction to develop policy guidance. *Ibid.*, pp. 5, 40.

³²⁶ *Ibid.*, p. 40 (statement of Haynes).

³²⁷ Lecea and Morales interview, p. 5 (statement of Morales).

³²⁸ *Ibid.*

³²⁹ *Ibid.*, p. 5.

from OCR. Technical assistance is not an ongoing activity, but is usually provided only when new or novel issues arise.³³⁰ OEECR does not expect any formal training from OCR until the MOU is completed and the nature of any delegated activities is clearer.³³¹ The OEECR director would like more regularly scheduled meetings with OCR.³³²

HCFA

HCFA's Office of Equal Opportunity and Civil Rights (OEOCR) has had much recent interaction with OCR as a result of a massive training effort that HCFA has undertaken to increase and update staff knowledge of civil rights laws. OCR has agreed to do the training, but only after considerable reluctance. The training involves 60 3-hour sessions for 2,400 HCFA employees, to be completed within a 1-year period.³³³ OCR initially refused to do the training because of a lack of resources. OCR only consented to do it after HCFA had investigated and rejected other avenues of offering the training; and agreed to pay any travel and per diem for the OCR trainers and to allow OCR regional staff to train HCFA regional staff.³³⁴ OEOCR's director hopes that the high level of interaction between the offices will remain after the training has ended, particularly when negotiating a new MOU.³³⁵

SAMHSA

SAMHSA reported that OCR "technical guidance and assistance have been readily available," so much so that the OPDIV does not need a formalized arrangement such as a cooperative agreement or a memorandum of understanding with HHS' OCR.³³⁶ OCR has met with SAMHSA staff recently when the extramural civil rights component was added to the equal employment opportunity functions of its office.³³⁷

³³⁰ *Ibid.*, pp. 5-6.

³³¹ *Ibid.*, p. 5.

³³² *Ibid.*, p. 6.

³³³ HCFA OEOCR interview, pp. 7-8 (statement of Suris-Fernandez).

³³⁴ *Ibid.*, p. 7 (statement of Suris-Fernandez).

³³⁵ *Ibid.*, p. 8 (statement of Suris-Fernandez).

³³⁶ SAMHSA, Response to Information Request, p. 1.

³³⁷ OPO interview, pp. 13-14 (statement of Nelson).

OCR Enforcement Activities, Generally

One area where OCR is not coordinating with the OPDIVS is in traditional enforcement activities. OCR continues to see the implementation of civil rights statutes as its own responsibility and does not see the OPDIVS as having the time, resources, or expertise to handle enforcement activities beyond the obtaining of assurances.³³⁸ According to OCR's director of Policy and Special Projects Staff, OPDIV staff are assigned to and "have a hard enough time" managing the programmatic elements of the provisions and services they deliver.³³⁹ "[T]hey should not be asked to handle civil rights responsibilities as well."³⁴⁰ OCR has the expertise that OPDIV staff do not have on civil rights compliance, implementation, monitoring and oversight, and enforcement matters. It would "take a while" to get OPDIV staff "up to speed," and they may not want to get "up to speed."³⁴¹ Finally, OCR staff do not believe that a more proactive role of OPDIV staff in civil rights implementation and enforcement responsibilities would necessarily result in fewer complaints of discrimination in HHS programs.³⁴²

OCR works cooperatively with OPDIVS during the pregrant process, to make sure that recipients and grantees are aware of what they must do.³⁴³ But, again, OCR is ultimately responsible for implementing civil rights statutes.³⁴⁴ OCR has limited the OPDIVS' role in enforcement responsibilities to ensuring that recipients provide necessary assurances of non-discrimination before awarding Federal funds.³⁴⁵ OCR, not the OPDIVS, devised the form that is used to obtain these assurances.³⁴⁶

³³⁸ For example, OCR's director of Policy and Special Projects Staff stated, "it is OCR's responsibility to implement civil rights statutes . . ." PSPS interview, p. 38 (statement of Haynes).

³³⁹ *Ibid.*

³⁴⁰ *Ibid.*

³⁴¹ *Ibid.*

³⁴² *Ibid.*

³⁴³ *Ibid.*, p. 7 (statement of Haynes).

³⁴⁴ *Ibid.*

³⁴⁵ Copeland and O'Brien interview, p. 2 (statement of Copeland); OPO interview, pp. 15, 25 (statements of Mackey and Shepperd); PSPS interview, pp. 37-39 (statement of Haynes).

³⁴⁶ OPO interview, pp. 15, 26 (statements of Mackey and Shepperd).

Technical Assistance

According to OCR staff, OCR is trying to make OPDIVS more aware of civil rights issues so they can target their programs to address such issues before there is a problem.³⁴⁷ Because OPDIV staff may be more familiar with equal employment opportunity issues than extramural civil rights matters, they have requested OCR's technical assistance in the latter area.³⁴⁸ For instance, OCR provided technical assistance to HCFA, HRSA, and AHCPR in the development of their respective strategic plans.³⁴⁹ These OPDIVS, in turn, provided input to the draft of OCR's strategic plan.³⁵⁰ OPDIV staff tend to approach regional staff, before OCR headquarters, when needing technical assistance.³⁵¹ For instance, an OPDIV could approach its HHS regional office and ask the civil rights staff what to do to determine if a day care center has been discriminating.³⁵² The OCR staff, in turn, would inform the OPDIV that "poor program administration" must be ruled out before a civil rights violation is determined.³⁵³

Outreach to OPDIV Funding Recipients

In developing and implementing its 1994 Strategic Plan, OCR regional managers worked with OPDIVS and sponsored "customer service outreach meetings," which served as a forum for HHS recipients and program administrators on HHS civil rights enforcement.³⁵⁴ All 10 regional offices invited stakeholders to attend such meetings.³⁵⁵

According to OCR staff, OCR works in partnership with other departmental elements in the development of important departmental initia-

³⁴⁷ HHS OCR July 29, 1998, interview, pp. 3-4 (statement of Copeland).

³⁴⁸ OPO interview, p. 13 (statement of Nelson).

³⁴⁹ PSPS interview, p. 40 (statement of Haynes).

³⁵⁰ *Ibid.*

³⁵¹ OPO interview, p. 15 (statements of Mackey and O'Brien); PSPS interview, p. 8 (statement of Haynes).

³⁵² *Ibid.*, p. 19 (statement of Mackey).

³⁵³ *Ibid.*, p. 20 (statement of Mackey).

³⁵⁴ O'Brien and Mackey interview, p. 7 (statement of O'Brien). The special assistant to the director of HHS OCR clarified that "customer service outreach sessions" were held specifically in conjunction with the development and implementation of OCR's most recent (1994) Strategic Plan. See Copeland and O'Brien interview, p. 4 (statement of O'Brien).

³⁵⁵ OPO interview, p. 57 (statement of Mackey).

tives on minority and women's health.³⁵⁶ Although some of these are internal initiatives to benefit the Department itself, many of them relate to the Department's extramural civil rights activities.³⁵⁷ For instance, the OCR strategic plan proposed that OCR work with the OPDIVS to ensure that HHS-sponsored programs do not discriminate on the basis of race, color, or national origin.³⁵⁸ In response to this proposal, OCR, along with the OPDIVS and the Assistant Secretary for Planning and Evaluation, is in the early stages of an initiative that addresses quality of care disparities facing racial/ethnic minorities.³⁵⁹ This effort is tied to the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health.³⁶⁰ OPDIVS are expected to determine how their services are being delivered to diverse groups and if their services are "culturally competent."³⁶¹

In 1995, as part of the Multiethnic Placement Act (MEPA)³⁶² Initiative, OCR, the Office of General Counsel, and the Administration on Children and Families went to each HHS region to meet State officials in adoption and foster care placement to inform them of their civil rights responsibilities under MEPA.³⁶³ OCR and OGC

³⁵⁶ O'Brien and Mackey interview, p. 9 (statement of Mackey).

³⁵⁷ *Ibid.*

³⁵⁸ HHS/OCR "Strategic Plan, 1994," pp. 7-8.

³⁵⁹ O'Brien and Mackey interview, p. 9 (statement of Mackey).

³⁶⁰ Copeland and O'Brien interview, p. 4 (statement of O'Brien). In 1998 HHS inaugurated its national effort to eliminate disparities in health access and outcomes in infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection, and child and adult immunizations. See HHS, "The Initiative to Eliminate Racial and Ethnic Disparities in Health," May 26, 1998, p. 1, accessed at <<http://raceandhealth.hhs.gov>>.

³⁶¹ OPO interview, pp. 17, 54 (statement of Mackey); PSPS interview, pp. 6, 34, 35 (statement of Haynes).

³⁶² Pub. L. No. 103-382, 108 Stat. 3518 (codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997)).

³⁶³ OPO interview, p. 15 (statement of Copeland). In 1995 OCR and ACF issued a policy guidance on the use of race, color, or national origin as considerations in adoption and foster care placements. See Mary Jo Bane, Assistant Secretary for Children and Families, and Dennis Hayashi, director, OCR, letter to addressees (re: Guidance on the Multiethnic Placement Act of 1994, 1995). The Multiethnic Placement Act of 1994 was enacted to prevent discrimination on the basis of race, color, or national origin as considerations in adoption or foster care placement. *Ibid.*, p. 1.

also provided outreach to each OPDIV on issues related to discrimination under title VI.³⁶⁴

In January 1998, the OCR director issued a formal memorandum to all OPDIV and headquarters office heads.³⁶⁵ This memorandum addressed the extent to which racial/ethnic minorities are being served in a nondiscriminatory manner in the 3,591 hospitals that received funds under HHS' Hill-Burton program (more than 60 percent of all hospitals nationwide) and were expected to comply with a community service assurance provision.³⁶⁶ The memorandum also summarizes the results of a 1996 survey administered to 380 non-Hill-Burton hospitals, which assessed the facilities' compliance with title VI, and obtained data on the number of persons provided emergency services and/or admitted as inpatients, by race/ethnicity, and method of payment.³⁶⁷

As of 1998, OCR conducts outreach and education activities in partnership with OPDIVS such as HCFA on such issues as HIV, renal dialysis, waivers, managed care, and other financial issues; and with ACF, OCR does outreach and education activities on welfare reform, adoption, and foster care.³⁶⁸ In addition, outreach meetings in 1998 addressed issues such as LEP, the Hill-Burton program, Healthy People 2000 and 2010, and the Children's Health Insurance Program.³⁶⁹ Overall, with respect to

³⁶⁴ OPO interview, p. 16 (statement of Copeland).

³⁶⁵ O'Brien and Mackey interview, p. 6 (statement of Mackey); PSPS interview, p. 35 (statement of Haynes); Dennis Hayashi, director, OCR, HHS, memorandum to OPDIV and STAFF heads, Jan. 22, 1998 (re: civil rights compliance reports) (hereafter cited as OCR, Hospital Memo). See chap. 4 for additional discussion of this memo.

³⁶⁶ OCR, Hospital Memo.

³⁶⁷ *Ibid.*; OMPE interview, p. 11 (statement of Melov). Although the memorandum states 384 hospitals, 4 of the facilities were actually closed. See OMPE interview, p. 11 (statement of Melov).

³⁶⁸ O'Brien and Mackey interview, p. 8 (statement of O'Brien); PSPS interview, pp. 14-15, 34-37 (statement of Haynes).

³⁶⁹ *Ibid.* In 1998 OCR issued an investigative memorandum on title VI prohibition against national origin discrimination, which focused on persons with limited English proficiency. See OCR, "Guidance Memorandum on Limited English Proficiency." To provide outreach on title VI's protections of and provisions for individuals with limited English proficiency, OCR regional offices held "roll-out LEP guidance memorandum briefings." Attendees at these sessions included State and local elected officials; Federal, State, and local government departments and agencies; representatives

HHS' outreach education activities that are conducted via the joint efforts of OCR and the OPDIVS, OCR tends to "piggyback" onto OPDIVS' outreach endeavors rather than vice versa.³⁷⁰ For instance, when OPDIVS hold conferences related to their specific programmatic areas, the HHS regional offices submit their monthly activities reports informing OCR headquarters of such activities during the planning stages.³⁷¹ OCR may want to be "at the table" during OPDIVS' conferences so that the agency can provide participants with a civil rights perspective of HHS provisions.³⁷²

Civil Rights Training of OPDIV Staff

OCR's last major, departmentwide training initiative was in 1993.³⁷³ The initiative consisted of three 1-day "civil rights forums," which were held for about a year on a quarterly basis.³⁷⁴ The forums served the Department's operating and staff divisions as well as title VI, Hill-Burton, and title IX funding recipients.³⁷⁵ The first civil rights forum was a 1-day "civil rights 101" session where staff of all OPDIVS, as well as DOJ and EEOC, had been invited and were represented.³⁷⁶ The session's objective was to explain basic civil rights requirements and responsibilities relevant to OPDIVS' programs.³⁷⁷ The latter two forums addressed the ADA and other disability statutes, but not title VI, title IX, Hill-Burton Act, or nondiscrimination provisions in block grant programs.³⁷⁸

The last training OCR offered OPDIVS on section 504 (part 85) was also in 1993.³⁷⁹ The

sessions focused on informing OPDIV staff about the responsibility of recipients of federally conducted programs to develop self-evaluations and transition plans.³⁸⁰ During the training period, OCR provided each OPDIV with onsite, 1-day training sessions, tailored to the specific programs they administer.³⁸¹ The training appears to have heightened the OPDIV staff's awareness of section 504, and as a result OCR has subsequently received numerous requests for technical assistance on this statute.³⁸²

Together, the 1993 forums and section 504 sessions covered "all of [OCR's] authorities and regulations, using fact sheets and case files."³⁸³ However, OCR provides little training on some civil rights statutes.³⁸⁴ For example, because OCR does "very little" work with title IX, it does not offer training on this civil rights statute.³⁸⁵ And, because the Hill-Burton program is being phased out, no training is provided on it.³⁸⁶ Yet, in the civil rights forums, participants from the OPDIVS expressed concerns to OCR about concepts such as medical redlining and race,³⁸⁷ suggesting that more training on the Hill Burton Act may be needed.

OCR has not provided any departmentwide civil rights training in the 6 years that have elapsed since the 1993 civil rights forums.³⁸⁸ Some more recent training has been offered, but was available only to a single OPDIV. For example, OCR held a 1-day training session for HCFA's providers on title VI and section 504 issues in December 1998.³⁸⁹

OCR apparently lacks a policy on the provision of civil rights training to OPDIV staff. An OCR representative acknowledged that OCR

of human rights/civil rights agencies; social service providers; refugee, immigrant, and provider associations and organizations; and other stakeholders. See HHS, OCR, Notes on Regional Roll-Outs on LEP Guidance Memorandum (HHS/OCR response to information request, question J-5).

³⁷⁰ OPO interview, p. 22 (statement of O'Brien).

³⁷¹ Ibid., pp. 22-23 (statement of O'Brien). Each month, HHS regional offices submit their Significant Activity Reports (SAR) to OCR headquarters.

³⁷² Ibid.

³⁷³ O'Brien and Mackey interview, p. 7 (statement of O'Brien).

³⁷⁴ Ibid.; OPO interview, pp. 10-12 (statement of Nelson).

³⁷⁵ O'Brien and Mackey interview, p. 7 (statement of O'Brien).

³⁷⁶ OPO interview, pp. 10-11 (statement of Nelson).

³⁷⁷ Ibid., p. 10 (statement of Nelson).

³⁷⁸ Ibid., pp. 10, 12 (statement of Nelson).

³⁷⁹ Ibid., p. 11 (statement of Nelson).

³⁸⁰ Ibid., pp. 11-12 (statement of Nelson).

³⁸¹ Ibid., p. 11 (statement of Nelson).

³⁸² Ibid., pp. 11-12 (statement of Nelson).

³⁸³ Ibid., p. 11 (statement of Nelson).

³⁸⁴ Ibid., pp. 2-3 (statement of Shepperd).

³⁸⁵ Ibid. Note that the U.S. Department of Education is largely responsible for enforcing title IX. Ibid., p. 3.

³⁸⁶ Ibid., p. 6 (statement of Shepperd).

³⁸⁷ Ibid., p. 12 (statement of Nelson).

³⁸⁸ O'Brien and Mackey interview, p. 7 (statement of O'Brien).

³⁸⁹ OPO interview, pp. 12-13 (statement of Nelson); Johnny Nelson, director, Division of Voluntary Compliance and Outreach, and Paul Cushing, Philadelphia regional manager; OCR, HHS, conference sponsored by Health Care Financing Administration, in Washington, DC, Dec. 10, 1998.

“does not routinely train [OPDIV] staff,” but tends to train only its “own staff” at headquarters.³⁹⁰ Regional offices “frequently” hold training sessions for their “regional counterparts,” to give them an overview of the civil rights authorities enforced by OCR and to ensure that OPDIV staff understand the application of civil rights statutes to the programs that they administer.³⁹¹ In turn, any training participants are expected to train colleagues who were unable to attend the training sessions.³⁹² An OCR representative said that the OCR current training record is “spotty” and unlike previous times when the agency trained each HHS office.³⁹³ Apparently, OCR had intended to provide program managers of the OPDIVS with “basic civil rights training” and work with them to create civil rights training programs focused on State agencies,³⁹⁴ but this has not occurred.

Apart from not have a training policy, OCR lacks any means of assessing training needs. In 1998 OCR did not have a mechanism to ensure that OPDIV staff are sufficiently trained to perform their duties of implementing civil rights

policy and enforcing it.³⁹⁵ OCR does not formally or regularly assess the deficiencies in OPDIV staff’s civil rights knowledge (e.g., understanding of statutes such as title VI, title IX, Hill-Burton Act, and nondiscrimination provisions in block grant statutes) or skills.³⁹⁶ In fact, neither of the two formal training needs assessments OCR has done since 1989 included OPDIV staff.³⁹⁷ OCR acknowledges that the office had not been active in developing or administering training needs assessments, but has relied upon informal input on training needs.³⁹⁸ Training needs are assessed on an ad hoc, as-needed basis even for OCR headquarters staff.³⁹⁹

Finally, at least one HHS staff person expressed concern that OCR does not even have training materials to disseminate.⁴⁰⁰ Instead of a comprehensive training manual, OCR relies upon its *Case Resolution Manual*.⁴⁰¹ Although this document is fairly recent (December 1996), OCR staff acknowledged that this manual should be supplemented with more formal training.⁴⁰²

³⁹⁰ OPO interview, pp. 2, 10 (statement of Shepperd).

³⁹¹ *Ibid.*, p. 2 (statement of Shepperd).

³⁹² *See* *ibid.*, p. 4 (statement of Shepperd).

³⁹³ *Ibid.*, p. 3 (statement of Shepperd). OPO staff mentioned that OCR’s budget for training has declined since 1989. An OPO staff member elaborated and said that in the mid- to late 1980s (1983–89), OCR’s budget was relatively stable and “more flexible,” and enabled OCR to provide training on a regular basis, and conduct a series of training sessions which ran over a period of 5 years. *See* *ibid.*, p. 3 (statement of Shepperd). During one series, OCR headquarters went to each regional office to provide an overview of title VI, section 504, the Age Discrimination Act, the nondiscrimination provisions of block grant statutes, and other relevant statutes. *Ibid.*, p. 3. OCR focused the sessions on “skill development” for investigators. *Ibid.*, p. 3. At other times, OCR provided training on specific areas, especially if new legislation (e.g., a statute related to the nondiscrimination provision of services to children with disabilities) was enacted. *Ibid.*, p. 3. However, OCR’s budget has recently been cut; and when a staff’s total budget is extremely limited, “training is usually the first thing to go.” *Ibid.*, p. 3. However, there may be a slight upturn in OCR’s 1999 budget for staff training. *Ibid.*, p. 8.

³⁹⁴ Hayashi letter, p. 5.

³⁹⁵ OPO interview, pp. 2, 5, 10, 13 (statement of Shepperd). Note that what skills OPDIV staff should have is unclear because they do not conduct compliance reviews and complaint investigations.

³⁹⁶ *Ibid.*, pp. 5, 6, 13 (statement of Shepperd).

³⁹⁷ One assessment was designed for investigators, and the other was for managers and supervisors. The latter instruments, administered in late 1997, queried regional managers on their specific training needs. *See* *ibid.*, pp. 5–6 (statement of Shepperd).

³⁹⁸ *Ibid.*, pp. 5–6 (statement of Shepperd). Apparently, regional investigators communicate their training needs informally. *Ibid.*

³⁹⁹ O’Brien and Mackey interview, p. 6 (statement of O’Brien). OCR was going to start a training plan, but computer upgrading and instruction is taking precedence. *See* OPO interview, p. 7 (statement of Shepperd).

⁴⁰⁰ OPO interview, p. 8 (statement of Shepperd).

⁴⁰¹ *Ibid.*, p. 8 (statement of Shepperd). OCR also has a hospital relocation manual and outline developed because of the recent effects of hospital relocations on minorities access to health care. *See* O’Brien and Mackey interview, p. 7 (statement of O’Brien).

⁴⁰² OPO interview, p. 8 (statement of Shepperd).

A Broader Context: The Future of Health Care Policy

"America is the land of modern medical technology, skilled surgeons, miracle medicines, and state-of-the-art medical facilities. It is also the land where access to even adequate health care is not available to all."¹

Ensuring equal access to quality health care and nondiscrimination in the distribution of health care services for women and minorities are an important part of a larger national goal: improving the quality and effectiveness of health care service delivery for every one of the millions of Americans who today remain without equal access to quality health care. As this report's review of literature addressing civil rights concerns in the context of health care indicates, significant barriers continue to prevent minorities and women from gaining access to quality health care. Every day, members of these groups are confronted with barriers to quality health care deriving from a number of factors, particularly race, color, national origin or cultural/linguistic background, and socioeconomic status.² Health care reform initiatives must address these barriers by including a strong, proactive civil rights component so that minorities and women no longer experience low quality, ineffective, or nonexistent access to medical care. Instead they should receive quality health care services without discrimination in *any* form on the basis of race, color, national origin, or sex.

¹ Judy Scales-Trent, "Women of Color and Health: Issues of Gender, Community, and Power," *Stanford Law Review*, vol. 43 (July 1991), p. 1357.

² See, e.g., Lawrence O. Gostin, "Securing Health or Just Health Care? The Effect of the Health Care System on the Health of America," *St. Louis University Law Review*, vol. 34 (fall 1994), pp. 7, 29–30. According to Gostin, there is a "powerful and growing literature on inequitable access to health care" on dimensions such as use, quality, and health outcomes. *Ibid.*, p. 29, citing Jonathan S. Feinstein, "The Relationship Between Socioeconomic Status and Health: A Review of the Literature," *Milbank Quarterly*, vol. 71 (1993), p. 279.

Recent Attempts to Reform Health Care Policy

In the early 1990s there emerged somewhat of a consensus in America on the need to reform the health care system. Unfortunately, however, while many Americans believed that the Nation's health care system should provide universal access to health care for all Americans, the consensus broke down over exactly how to achieve this goal. Notions from the left side of the political spectrum envisioned a system in which government would play a prominent role, such as Clinton's Health Security Act.³ This concept met strong opposition from conservatives who were worried that overregulation would harm the health care industry. In his January 25, 1994, State of the Union address, President Clinton pressed Congress for legislation that would provide universal health insurance coverage:

If we just let the health care system continue to drift [in its present direction, Americans] will have less care, fewer choices and higher bills. . . . If you send me legislation that does not guarantee every American private health insurance that can never be taken away, you will force me to take this pen, veto the legislation, and we'll come right back here and start all over again.⁴

In contrast, former Senator Robert J. Dole, in a notable comment following President Clinton's address said:

We know that America has the best health care system in the world; that people from every corner of the globe come here when they need the very best treatment; and that our goal should be to ensure that every American has access to this system. Of course, there are Americans with a sick child or sick parent

³ S. 2296, 103rd Cong. (1993); H.R. 3600, 103rd Cong. (1993).

⁴ Gostin, "Securing Health," p. 7, citing "The State of the Union Address: 'Let Us Resolve to Continue the Journey of Renewal,'" *Washington Post*, Jan. 26, 1994, p. A-12.

in real need, both in rural and urban America. Our country has health care problems, but no health care crisis.⁵

Ultimately, the President and lawmakers could not agree on how best to improve access to quality health care. The short-lived consensus on fundamental change failed, as pundits and policymakers began to realize that modifying the health care system would not be a revolution, but a long war, with battles fought on many fronts. In the wake of this failure, health care reform advocates set upon a new political strategy with an incremental approach. This tactic, which attacked various aspects of the health care status quo piecemeal, has met with some success.⁶ These policy initiatives should be acknowledged as attempts to contain escalating health care costs, expand insurance coverage with more comprehensive services available to more individuals, and adjust the maldistribution of health and medical care providers (primary and specialty care).⁷ However, these plans have

⁵ *Ibid.*, pp. 7–8, citing “Dole: Nation ‘Has Health Care Problems, but No Health Care Crisis,” *Washington Post*, Jan. 26, 1994, p. A–13.

⁶ Examples of enacted laws relating to health care reform include the Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104–191, title VI, § 601, 110 Stat. 1936 (codified at 42 U.S.C. §§ 300gg–300gg–92 (Supp. II 1996)); and the State Children’s Health Insurance Program (CHIP), Pub. L. No. 105–33, §§ 4901, 4911–4913, 4921–4923, 111 Stat. 552–575 (codified at 42 U.S.C. §§ 1301, 1320a–7, 1396a, 1396b, 1396d, 1396r–1a, 1397aa, 1397bb, 1396a, 254c–2, 254c–3 (Supp. III 1997)). For recent proposals, see the Health Professions Education Partnerships Act of 1998 (S. 1754, 105th Cong., 2d Sess (1998)); the Medical Information Privacy and Security Act (S. 573, 105th Cong. 2d Sess (1998)). See also the various Patients’ Bill of Rights Acts in notes 8 and 9 below.

⁷ Factors that contribute to the rising costs of health care include technological advances (expanding use of technological procedures for diagnosis and treatment such as magnetic resonance imaging); medical inflation (costs for drugs, equipment, and highly skilled personnel exceed the rate of general inflation); and an increase in the population over age 65 (who are likely to suffer the complications of chronic illness, have frequent hospital stays, and have higher surgical rates than younger patients). The elderly are treated more aggressively in the last years of their lives than they are in many other nations. See Norma and Marshall Raffel, “The Health System of United States,” in Marshall Raffel, ed., *Health Care Reform in Industrialized Nations* (University Park, PA: Pennsylvania State University Press, 1997), pp. 276–77. Expenditures for health services and supplies were \$236 billion in 1980, \$412 billion in 1985, \$675 billion in 1990, \$961 billion in 1995, and \$1,035 billion in 1996. See U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Statistical*

various weaknesses that must be overcome if Congress is to reform the health care system in a fashion that would incorporate civil rights ideals such as ensuring equality in access to and quality of health care, as well as nondiscrimination for women and minorities.

The Patients’ Bill of Rights

A patients’ “Bill of Rights” has become the central concept to health care reform. Four bills known as Patients’ Bill of Rights or Patient Protection Acts were introduced in Congress in 1998—one each by the Republicans and Democrats in the House and the Senate.⁸ Similarly, several bills designated as Patients’ Bill of Rights were introduced in 1999.⁹

Abstract of the United States 1998, 118th edition, table no. 165, p. 118 (hereafter cited as *Census, Statistical Abstract*). The Nation’s rate of health care spending has been slowing since the period from 1980 to 1990 when it grew an average of 11 percent per year; the Nation’s total health care expenditures grew by only 4.8 percent in 1997; however, expenditures still hit an all-time high of nearly \$1.1 trillion. See “National Health Care Spending Growth At Low Level in 1997, EBRI Report Says,” *Daily Labor Report*, Mar. 31, 1999, p. A–4. In the public sector, the Federal Government’s health care expenditures (in billions of dollars) rose from 42 in 1980, to 68 in 1985, to 115 in 1990, to 203 in 1995. *Census, Statistical Abstract*, table no. 168, p. 119.

⁸ See Patients’ Bill of Rights Act of 1998 (S.1890, 105th Cong. (1998) and H.R. 3605, 105th Cong. (1998)) introduced by Democrats on Mar. 31, 1998; and the Patient Protection Act of 1998 (H.R. 4250, 105th Cong. (1998)) and the Patients Bill of Rights Act (S. 2330, 105th Cong. (1998)) introduced by Republicans on July 16 and 17, 1998, respectively. The Patient Protection Act of 1998, introduced by Rep. Gingrich, passed the House on July 24, 1998, but did not pass the Senate. See “Bill Summary & Status for the 105th Congress,” “H.R. 4250,” accessed at <<http://thomas.loc.gov/cgi-bin/bdquery/D?d...:/temp/~bd2kY9:@@L|/bss/d105query.html>>.

⁹ In January 1999, the Democrats introduced S.6, 106th Cong. (1999), 145 CONG. REC. S338 (daily ed. Jan. 19, 1999); S. 240, 106th Cong. (1999), 145 CONG. REC. S345 (daily ed. Jan. 19, 1999); and H.R. 358, 106th Cong. (1999), 145 CONG. REC. H268 (daily ed. Jan. 19, 1999), all of which were “Patients’ Bill of Rights” bills. Also in January, Republicans offered the Patients’ Bill of Rights Plus Act (S. 300, 106th Cong. (1999)) that Sen. Lott introduced (see 145 CONG. REC. S895 (daily ed. Jan. 22, 1999)) and a Patients’ Bill of Rights Act (S. 326, 106th Cong. (1999)) introduced by Sen. Jeffords (see 145 CONG. REC. S1076 (daily ed. Jan. 28, 1999)). See also Karen Foerstel, “Debate on Patients’ Protection Bursts Into Open as Rep. Ganske Gives GOP Dreaft to Reporters,” *CQ Weekly*, May 1, 1999, p. 1025. The Republicans introduced further patient protection legislation in the Senate during the summer: S. 1274, 106th Cong. (1999) (see 145 CONG. REC. S7590 (daily ed. June 24, 1999)); and S. 1344, 106th Cong. (1999) (see 145 CONG. REC. S8260 (daily ed. July 8, 1999)). Note that the Jeffords bill is also known as the “Healthcare Research and Quality Act of 1999.” S.

The issues that the various Democratic proposals for Patients' Bill of Rights Acts addressed were much the same, particularly with respect to their attention to civil rights concerns about nondiscrimination and equal access to health services. For example, key Democratic provisions included a proposal to strengthen the rights of patients in managed care plans through an initiative that would have given physicians rather than insurance companies the final say over patients' treatments,¹⁰ and a proposal to give women more freedom in choosing primary care doctors.¹¹ The Senate voted down these proposals when it passed a Republican version of the Patients Bill of Rights in July 1999.¹² However, President Clinton stated that he would veto any legislation presented to him based on this bill.¹³ Therefore, the Democratic vision for the Patients Bill of Rights may yet prevail in a future congressional session.

While neither the Democrats' nor the Republicans' bills fully addressed the need to incorporate a strong civil rights emphasis in this legislation, the Democrats' proposed provisions were more in accord with the Commission's views on the specific ways in which the Nation must reform its health care system to combat discrimination against women and minorities in the health care industry. These provisions therefore provide an appropriate point of departure for a discussion suggesting the means for achieving this reform.

The 1999 Democrats' versions will be discussed here for two other reasons. First, they garnered widespread support for their Patients' Bill of Rights, including, for example, nearly 200 cosponsors and endorsements from over 150 organizations by mid-1998.¹⁴ Second, their 1999 versions, introduced in both the House and the Senate in January,¹⁵ had reforms that reached further than what the Republicans have or will propose in their compromise bills.¹⁶

The proposed 1999 Democratic bills for Patients' Bill of Rights included provisions for patients to obtain:

- Access to emergency care services without any prior authorization, in any situation that a "prudent lay person" would regard as an emergency.¹⁷
- Referrals to providers who have the "requisite expertise" to treat patients' special conditions, including referrals for enrollees to go outside of their respective plans' network (at no extra cost) if there is no appropriate provider available in the network for covered services.¹⁸
- Access to clinical trials, especially if participation in such studies is the only known treatment available. Plans are prohibited from discriminating against enrollees who participate in medical trials.¹⁹
- Right to confidentiality. Health plans must establish procedures to safeguard the privacy of individually identifiable medical information and records, maintain this information in an accurate and timely manner, and assure enrollees, participants, and beneficiaries timely access to such information.²⁰
- Decisions about "medically necessary" services, procedures, and benefits made between physicians and patients, rather than by group health plans or health insurance insurers.²¹

326, 106th Cong. (1999). See vol. II, chap. 3, for a discussion of S. 326 as it relates to the issue of appropriate care.

¹⁰ See S. 6 § 151(a)-(c); H.R. 358 § 151(a)-(c). See also discussion below for a fuller treatment of this provision; Helen Dewar and Amy Goldstein, "Measures on Patients' Rights Lose in Senate," *Washington Post*, July 14, 1999, pp. A-1, A-4. (hereafter cited as Dewar and Goldstein, "Measures").

¹¹ See 145 CONG. REC. S8325-27 (daily ed. July 13, 1999) (statement of Sen. Robb), 145 CONG. REC. S8327-28 (daily ed. July 13, 1999) (statement of Sen. Murray); S. 6 § 104(a)(1)(A), H.R. 358 § 104(a)(1)(A). See also discussion below for a fuller treatment of this provision; Dewar and Goldstein, "Measures," pp. A-1, A-4.

¹² As this report was being prepared for publication, the U.S. Senate voted to pass S. 1344. See 145 CONG. REC. S8622 (daily ed. July 15, 1999).

¹³ In response to the passage of the bill, President Clinton was quoted as stating "[i]f Congress insists on passing such an empty promise to the American people, I will not sign the bill . . . Passing a strong, enforceable patients' bill of rights should not be a partisan issue." Alison Mitchell, "Senate Approves Republican Plan for Health Care," *New York Times*, July 16, 1999, p. A-1.

¹⁴ 144 CONG. REC. H5053 (1998) (statement of Rep. Pallone).

¹⁵ Rep. John D. Dingell (D-Mich.) introduced the House version of the bill. See H.R. 358, 106th Cong. (1999). Sen. Tom Daschle (D-S.D.) introduced the Senate bill. See S. 6, 106th Cong. (1999).

¹⁶ Foerstel, "Debate on Patients' Protection," p. 1025.

¹⁷ S. 6 § 101; H.R. 358 § 101.

¹⁸ S. 6 § 104; H.R. 358 § 104.

¹⁹ S. 6 § 106; H.R. 358 § 106.

²⁰ S. 6 § 122; H.R. 358 § 122.

²¹ S. 6 § 151(a)-(c); H.R. 358 § 151(a)-(c).

Section 151 of the Patients' Bill of Rights would prohibit health plans from arbitrarily interfering with or altering decisions of treating physicians, when such decisions concern a covered benefit that is "medically necessary or appropriate" according to generally accepted principles of professional medical practice.²²

Assessing the Patients' Bill of Rights from a Civil Rights Perspective

Provisions in versions of the Patients' Bill of Rights introduced in both the House and Senate by the Democrats in 1999 represent an excellent beginning in the quest to ensure equal access to quality health care. The proposed provisions sought to prohibit discrimination in the delivery of services with respect to health insurance coverage,²³ allow female enrollees to designate a gynecologist or obstetrician as the primary provider in health plans that provide for enrollees to designate a primary care provider,²⁴ require mandatory collection of data by health care plans and health insurance issuers,²⁵ and also require the dissemination of information by group health plans or health insurance issues to participants on the plans' service areas and benefits covered.²⁶

However, to further these ambitious goals, future reform legislation must provide even more comprehensive protections than those the Democrats' 1999 Patients' Bill of Rights proposals afforded. Despite the merits of the aforementioned provisions, it appears that the drafters neglected to include sufficient strategies to: (a) remedy the prevailing gaps in access to care and provision of service and (b) ensure that health care is delivered in a nondiscriminatory manner. The common thread running through the current policies, similar to prior proposed initiatives, is the lack of provisions to sufficiently address socioeconomic,²⁷ cultural/linguistic, and

logistical (e.g., transportation) barriers in access to health care providers and facilities. In addition, proposed policy reforms have neglected to mandate that health care providers deliver culturally competent services to the Nation's growing ethnic minority populations, to ensure that preventive and treatment services are comprehensible, relevant, and meaningful to them.

Furthermore, the drafted policies lacked appropriate standards for determining civil rights compliance, particularly for policies and practices in the current health care system that can have a disparate impact on minorities and women. Finally, the proposed policies, did not require providers or insurers to maintain adequate gender- and race-based data on patients' access to health care facilities and receipt of specific medical procedures. In addition, the proposed policies did not mandate that Federal, State, or local agencies regularly collect, aggregate, maintain, and report such information. Overall, these policies reflected efforts to reduce the burden of growing health care costs, but conflicted with efforts to guarantee individuals the right to accessible, affordable, nondiscriminatory, quality health care.

Nondiscrimination Clause

The Patients' Bill of Rights contained a brief nondiscrimination provision that prohibited group health plans and health insurance issuers from discriminating against enrollees, beneficiaries, and participants in relation to health care coverage and in the delivery of health care services consistent with the benefits covered under each individual's selected health plan.²⁸ Discrimination was prohibited on the basis of the following classifications: race, color, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic background, or source of payment.²⁹

Lack of Provisions Ensuring Equal Access to Providers or Particular Services for a Given Set of Symptoms

The explicit language of this nondiscrimination provision indicated that it is limited in application to group health plans and health insurance issuers and did not apply to health care providers (physicians or other health care pro-

²² S. 6 § 151(a)-(c); H.R. 358 § 151(a)-(c).

²³ S. 6 § 109; H.R. 358 § 109.

²⁴ S. 6 § 104(a)(1)(A); H.R. 358 § 104(a)(1)(A).

²⁵ S. 6, § 112; H.R. 358 § 112.

²⁶ S. 6 § 121; H.R. 358 § 121.

²⁷ A scholar at Georgetown University Law School and former member of the President's Task Force on National Health Care Reform noted that the relationships between low socioeconomic status and poor health are "deep and enduring." Gostin, "Securing Health," p. 30.

²⁸ S. 6 § 109(a); H.R. 358 § 109(a).

²⁹ S. 6 § 109; H.R. 358 § 109.

professionals).³⁰ As a result, it did not adequately address the barriers confronting minorities and women in every aspect of the health care system. For example, the proposed language did not ensure equal access to physician or hospital visits in general, nor did it ensure equitable access to specific health care procedures for a given condition, disease and severity level, and set of symptoms. Thus, the proposed reform did not directly protect women and minorities from being discriminated against in the type, quantity, and quality of health care services delivered by their practitioners.

Lack of Assurance of Providers Who Can Deliver Culturally Competent Care

Barriers to health care providers and facilities, and to the health care services that they provide, affect individuals within distinct ethnic and cultural groups differently.³¹ According to a legal scholar at the University of Dayton, when attempting to remedy racial barriers, it is essential for policies to refrain from assuming that all racial/ethnic minorities are affected equally, because these minorities are not a homogeneous group.³² The proposed 1999 Patients' Bill of Rights did not adequately ensure that health care practitioners deliver culturally competent care and are sensitive to the different cultural patterns among racial/ethnic minorities and the effects these patterns can have on how health care services are provided.³³ In addition, the

proposed reform did not appropriately address the fact that language-minority individuals may be denied meaningful access to health care if they are not provided with assistance in communicating with their doctors (e.g., in explaining symptoms, pain levels, medical history) or provided with treatment and services appropriate to their respective cultural backgrounds.³⁴ As one commentator has observed:

[T]he health care system is designed around the cultural needs of middle-class European Americans. Ethnic Americans and poor individuals seem less compliant and more difficult to care for because they have differing needs and problems in accessing care . . . The problem, however, is not poor patients or ethnic Americans, but the health care system's inability to provide effective care to diverse populations. If increased compliance and improved health status are the goals, then the health care system must be flexible enough to match a community's cultural, ethnic, lifestyle and socioeconomic needs.³⁵

Another commentator who specializes in health care law claims that one of the most effective ways to reduce disparities in the utilization of medical care is by increasing medical educators' and providers' awareness of the effects of cultural differences on health care. This will prompt a response to the persistent inequities in the delivery of health care services.³⁶ According to another expert, miscommunication between physicians and patients can stem from providers' lack of knowledge about other cultures' "deference to authority, descriptions of pain, and views about wellness and illness."³⁷ Furthermore, a lack of bilingual health care providers, "cultural ignorance" and delivery of "culturally irrelevant" medical services, as well as diagnostic misinterpretations of the effects of alternative medicines, can all inhibit minority access to health care, contribute to existing barriers, and

³⁰ S. 6 § 191(c)(3); H.R. 358 § 191(c)(3).

³¹ Vernellia R. Randall, "Does Clinton's Health Care Reform Proposal Ensure Equality of Health Care for Ethnic Americans and the Poor?" *Brooklyn Law Review*, vol. 60 (spring 1994), p. 213 (hereafter cited as Randall, "Clinton's Health Care Reform Proposal").

³² *Ibid.*, p. 213, citing Jose E. Becerra et al., "Infant Mortality Among Hispanics: A Portrait of Heterogeneity," *Journal of the American Medical Association*, vol. 265 (1991), p. 217; and B. Josea Kramer, "Health and Aging of Urban American Indians," *Western Journal of Medicine*, vol. 157 (1992), p. 281.

³³ The term "culture" can be defined as a body of learned values, beliefs, and behaviors that distinguish a group of people. Culture provides the framework by which individuals interpret their surroundings, the behavior of others, and events that happen. See Randall, "Clinton's Health Care Reform Proposal," p. 205, citing Vernellia R. Randall, "Ethnic Americans, Long Term Health Care Providers and the Patient Self Determination Act," in Marshall Kapp, ed., *Long Term Health Care Providers and the Patient Self Determination Act* (1994); and Henry S. Perkins, "Cultural Differences and Ethical Issues in the Problem of Autopsy Requests," *Texas Medicine/The Journal*, vol. 87 (1991).

³⁴ See generally Randall, "Clinton's Health Care Reform Proposal."

³⁵ *Ibid.*, p. 208.

³⁶ Barbara A. Noah, "Racist Health Care?" *Florida Law Review*, vol. 48 (July 1996), p. 367; H. Jack Geiger, "Race and Health Care—An American Dilemma?" *New England Journal of Medicine*, vol. 335 (Sept. 12, 1996), p. 816 (citations omitted).

³⁷ Sidney Dean Watson, "Minority Access and Health Reform: A Civil Right to Health Care," *Journal of Law, Medicine and Ethics*, vol. 22, no. 2 (summer 1994), p. 128 (hereafter cited as Watson, "A Civil Right to Health Care").

perpetuate discriminatory practices.³⁸ Thus, it is essential that providers become attuned to the variety of cultures affecting health care needs, minority expectations of medical care, and the fact that prior experiences with health care delivery (in other cultural settings) can affect approaches to accessing and interacting with the health care system.³⁹

Lack of Provision to Remedy Linguistic Barriers Between Provider and Patient

Another potential barrier related to minority culture is language. Although many national origin minority individuals have limited English proficiency and cannot effectively communicate with their physicians, neither the proposed 1999 Patients' Bill of Rights nor any current statute sets out specifically how providers or health plans must address such barriers.⁴⁰ According to an attorney with the National Health Law Program, overcoming language barriers to health care is critical to the well-being of individuals with limited English proficiency who encounter substantial communication problems at almost every level of the health care delivery system, from administrative (in scheduling an appointment) to clinical (when attempting to convey symptoms, personal medical history, or genetic profile to health care providers).⁴¹ Communication barriers can prevent health care providers from delivering quality health care in an appropriate, nondiscriminatory, and equitable manner.⁴² In particular, language barriers can defeat

the provision of health care if essential information about treatment cannot be conveyed.⁴³

The proposed 1999 Patients' Bill of Rights lacked provisions to facilitate communication between national origin/language minority patients and English-speaking health care providers. In particular, the bill lacked provisions requiring: (a) interpreter services to assist with every aspect of health care (for example, scheduling followup appointments with a provider or alternate specialist, contemplating inpatient care, paying for medical services); (b) translation of personal medical information or records from office visits; and (c) translation of general health care documents and brochures into the most common languages of the geographic area surrounding a given health care facility.

The Patients' Bill of Rights could be credited for granting patients access to printed information on health plans, including coverage policies and quality indicators.⁴⁴ However, this provision did not indicate that information would be available in languages other than English. Without a mandate for health care information to be translated into languages for beneficiaries who have difficulty communicating in English, not every individual can be equally informed and able to effectively participate in critical decisions related to his or her health care. Thus, the proposed 1999 version of the Patients' Bill of Rights would potentially deprive some individuals of the ability to make appropriate decisions involving health care.

Protections for Women

The proposed 1999 Patients' Bill of Rights provided important protections designed to protect women against discrimination in the managed care setting. For example, it contained a provision allowing women to designate an obstetrician/gynecologist as a primary care provider.⁴⁵ The proposed bill also set minimal hospital lengths-of-stay for women undergoing mastectomy or other surgical procedures in connection with breast cancer.⁴⁶ However, the legislation did not address the fact that gender plays a role in other nongynecological health issues—from

³⁸ Ibid., p. 128.

³⁹ Francesca Gany and Heike De Bocanegra, "Overcoming Barriers to Improving the Health of Immigrant Women," *Journal of the American Medical Women's Association*, vol. 51 no. 4 (August/October 1996), pp. 157. Physicians should also be alerted to the tendencies of recent immigrants to resist traditional Western medicine and instead rely on home remedies. For instance, religious attitudes toward health, care, and treatment can cause some Asian groups to avoid the health care system. See Watson, "A Civil Right to Health Care," p. 128.

⁴⁰ Randall, "Clinton's Health Care Reform Proposal," p. 209. Approximately 25 percent of Hispanic Americans do not understand English sufficiently to speak with their physicians. Ibid., p. 209, citing Jaime A. Davidson, "Diabetes Care in Minority Groups: Overcoming Barriers to Meet These Patients' Special Needs," *Postgraduate Medicine*, vol. 90 (1991), p. 162.

⁴¹ Jane Perkins et al., National Health Law Program, "Ensuring Linguistic Access in Health Care Settings: Legal Rights and Responsibilities," brochure, January 1998.

⁴² Ibid.

⁴³ Randall, "Clinton's Health Care Reform Proposal," p. 209.

⁴⁴ S. 6 § 121; H.R. 358 § 121.

⁴⁵ S. 6 § 104(a)(1)(A); H.R. 358 § 104(a)(1)(A).

⁴⁶ S. 6 § 152(a)(1)(A)-(C); H.R. 358 § 152(a)(1)(A).

the types and prevalence of diseases women experience, to the differences in symptoms and types of treatments that are most appropriate for them.⁴⁷ According to the National Partnership for Women and Families, many providers still practice medicine based on the traditional "male model" of biology and disease.⁴⁸ Consequently, medical care delivered and preventive services rendered could have a disparate adverse impact on women. The proposed 1999 Patients' Bill of Rights did not address this potential inequity by including an appropriate provision, such as a requirement for board certified physicians to have a comprehensive understanding of the distinctions in male and female physiology, health behaviors, and health risks.

Data Collection

Various commentators and researchers have made the following findings with respect to the need to reform current data collection, analysis, and reporting practices in the health care industry:

HCFA Form 1450 does not record the race or ethnicity of the patient receiving the care. This omission perpetuates the government's inability to monitor health care providers' civil rights compliance, and cripples minority health research.⁴⁹

It was ridiculous because this information would have meant so much to CDC and the rest of the medical science world, not to mention the civil rights community, and it would have been so easy to just add the race data element to the universal billing form, which the whole industry already used.⁵⁰

While the Medicare program publishes data on white and nonwhite use of resources, it produces no routine reports on the ethnic distribution of beneficiaries by facilities. The incompleteness of the information on

the race or ethnic backgrounds of recipients limits analysis.⁵¹

Health systems agencies . . . avoided the analysis of data on facility segregation. According to the administrator of this program, "an attempt to do so would threaten the availability of the data they need from health facilities for health planning purposes as well as their ability to develop a broad-based acceptance of health planning activities."⁵²

There is no Federal requirement for uniform data collection and little Federal monitoring of the data collection activities that take place at the State level. Title VI compliance records remain mostly in the manual filing systems of the State agencies without any systematic effort to summarize them.⁵³

The proposed 1999 Patients' Bill of Rights required that health care plans and insurers collect data in a standard format for reporting to the States, the Secretary of HHS, and where appropriate, consumers and providers.⁵⁴ Standardized information must be collected on elements such as use of services; demographic characteristics of participants, beneficiaries, and enrollees; health outcomes; participants' level of satisfaction with services; and number of voluntary disenrollments and grievances.⁵⁵ This information is essential for monitoring the quality of health plans and comparing success across plans. However, the proposed data collection requirement is not sufficient for effective civil rights enforcement in the context of health care delivery. For instance, the provision does not specify the type of demographic information that must be collected on health care consumers (e.g., patient gender, racial background, age, income, education level, address), or the frequency (e.g., every physician or hospital visit, physician visits for nonroutine care only, hospital visits only). Because of the broad language of the proposed data collection requirement (similar to that of title VI's compliance information requirements⁵⁶), health care providers or insurers would not be

⁴⁷ National Partnership for Women and Families, "Women's Health and Managed Care: Principles for Quality Health Care," no date, pp. 1, 4.

⁴⁸ *Ibid.*, p. 4.

⁴⁹ Jane Perkins, Sidney Watts, and Gordon Bonnyman, memorandum to Individuals and Organizations Interested in Civil Rights and Minority Health *Amici Curiae* in *Madison-Hughes v. Shalala*, Feb. 9., 1994 (re: Update on *Madison-Hughes v. Shalala*: ACTION NEEDED).

⁵⁰ Gordon Bonnyman, managing attorney, Tennessee Justice Center, Nashville, TN, telephone interview, Feb. 14, 1999, p. 12 (hereafter cited as Bonnyman interview).

⁵¹ David Barton Smith, "Racial Integration of Health Facilities," *Journal of Health Politics, Policy, and Law*, vol. 18, no. 4 (winter 1993), p. 853.

⁵² *Ibid.*

⁵³ *Ibid.*, p. 854.

⁵⁴ S. 6 § 112; H.R. 358 § 112.

⁵⁵ *Id.*

⁵⁶ See 28 CFR § 42.406, 42.407 (1998).

mandated to keep records and submit them to health care agencies on the gender status or racial/ethnic backgrounds of patients admitted and treated with a particular service for a given condition and severity level or set of symptoms.

Similarly, because the proposed health care reform bills do not require that Federal, State, and/or local health care agencies systematically or uniformly collect, report, or disseminate gender- and race-based data by health care providers or facilities, the extent of discrimination in health care service use could not be detected. According to an attorney with the National Health Law Program, Federal agencies', such as HHS, neglect of collecting data on the racial/ethnic backgrounds on health care service beneficiaries is long standing.⁵⁷ The proposed Patients' Bill of Rights only perpetuated this deficiency, because it did not: (a) require each individual health care provider to record, much less report, data that would be minimally necessary to assess compliance with title VI, nor did it (b) compel Federal agencies to collect race/ethnicity data on client use across the health care industry, which can cause charges of discrimination to go unreported and remain unaddressed due to lack of evidence to prove a title VI violation.⁵⁸

One advocate for data collection argues that minority Americans are concerned about providers' failure to collect race/ethnicity data on patients' claim forms for every medical transaction because of the evidence of disparity or discrimination it could provide.⁵⁹ Another law commentator had similar views on the importance of mandating the systematic collection, aggregation, analysis, and reporting of race-based data

⁵⁷ Jane Perkins, "Race Discrimination in America's Health Care System," *Clearinghouse Review*, special issue 1993, p. 377. According to a civil rights attorney at Temple University, in 1981 the Institute of Medicine (IOM) reviewed ethnic data that had been collected and analyzed on participants in federally assisted programs. The IOM revealed that there was a dearth of quantitative information on the extent of segregation in health care; its regional, State, and local variations; and how Federal policy affects it. See Smith, "Racial Integration of Health Facilities," p. 853, citing Institute of Medicine, *Health Care in the Context of Civil Rights* (Washington, DC: National Academy Press, 1981). Eleven years later, the IOM's finding was still considered relevant. See Smith, "Racial Integration of Health Facilities," p. 853.

⁵⁸ Perkins, "Race Discrimination," p. 377.

⁵⁹ Randall, "Clinton's Health Care Reform Proposal," p. 189, citing Gordon Bonnyman, Jr., "Unmasking Jim Crow," *Journal of Health Politics, Policy, and Law*, vol. 18, no. 4 (winter 1993), p. 872; Bonnyman interview, p. 1.

in the context of health care, to enforce civil rights in this area. She claimed that tracking the progress of the Nation's efforts to improve the health of minorities and dismantle barriers to health care access and treatment is essential.⁶⁰ The States' plans to reduce health disparities should be, among other civil rights remedies and reform initiatives, geared to improving minority access to care, treatment, and health status. She also noted that States need mandatory collection and dissemination of data on minority access and treatment to determine and revise their disparity reduction goals and develop a plan for action.⁶¹

In ensuring equal access to health care providers and services without discrimination on the basis of the classifications included in the proposed 1999 Patients' Bill of Rights, it appears critical that health care reform policies require providers (including hospitals, home health agencies, health care maintenance organizations, nursing homes, and other health care facilities) to consistently collect and submit to appropriate "gatekeeper" State and Federal agencies, data on: (a) patients' gender and racial/ethnic background in conjunction with (b) patients' health status (symptoms, disease severity level) and (c) the particular services (e.g., diagnostic, preventive, rehabilitative, therapeutic, primary/ambulatory care, and mental health); specific procedures (e.g., laboratory tests, x-rays, including MRI and mammography, dialysis, surgeries, organ transplants, and amputations); and treatments delivered. All of these data are important to determining whether women and men and all racial/ethnic groups are admitted to health care facilities and obtain physician office visits at proportionate rates.

Summary

Overall, health care reform efforts have been motivated largely by narrowly focused concerns about the Nation's "ever increasing" health care

⁶⁰ Watson, "A Civil Right to Health Care," p. 133.

⁶¹ Ibid. For additional information on the role of data collection, analysis, and maintenance in enforcing women and minorities' access to and receipt of health care services, see USCCR, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. I The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999, chap. 4 (hereafter cited as USCCR, *The Health Care Challenge, Vol. I*).

expenditures,⁶² the costs imposed on employers and the government, and the problems associated with uncompensated care.⁶³ Health care reform efforts thereby have been associated with a push for cost containment, while the aim to ensure “universal access” is a more recent phenomenon.⁶⁴ According to a professor at Mercer University Law School, a health care initiative that includes “universal coverage” could reduce a major barrier to care for racial/ethnic minorities—the inability to pay for such services.⁶⁵ However, it is critical that Federal health policy acknowledge that “universal financing” (even with “comparable fee-for-service payment” or “appropriately risk-adjusted capitated reimbursement”) does not automatically ensure that racial/ethnic inequities and economic discrimination are eliminated.⁶⁶ Persistent restrictive admission practices, racial and cultural stereotypes, and the failure to employ minority health professionals, as stated throughout this report, all continue to pervade health care delivery (especially in inner cities) and contribute to impeding minorities’ access to the health care system.⁶⁷

A Civil Rights Component to Health Care Reform

Legislation Addressing Barriers to Equal Access and Quality Health Care

Any comprehensive efforts to reform the health care system must focus attention on dismantling the barriers that women and minorities confront in obtaining equal access to quality diagnostic, preventive, and primary health care. Further, civil rights provisions should be an in-

tegral part of health care reform policy. According to one legal scholar, they represent the best hope for reducing the significant noneconomic barriers to care.⁶⁸ Lessons learned from the shortfalls in other statutes (such as title VI) in redressing the inequities in minority access and medical treatment should be used to craft and implement a revised civil rights statute in the context of health care reform.⁶⁹ That is, health care reform efforts cannot rely solely on title VI or other civil rights statutes, such as Hill-Burton and title IX, as a “civil rights remedy” to ensure minority individuals’ equal access to and participation in the health care delivery system.⁷⁰ Rather, additional civil rights protections must be developed and implemented to clarify and strengthen the protections offered by title VI, Hill-Burton, or title IX in the context of health care delivery.⁷¹

New legislation that would reflect the Nation’s commitment to ensuring that the highest quality health care services are made available on a nondiscriminatory basis can do so by expanding upon existing civil rights laws in two ways. First, any comprehensive civil rights protections in the health care context must reach beyond the coverage of laws such as title VI and Hill-Burton. For example, title VI is limited only to federally assisted entities because Congress derived its authority for this statute under its constitutional spending power.⁷² However, by

⁶² See note 7, above.

⁶³ Randall, “Clinton’s Health Care Reform Proposal,” p. 212; Sidney D. Watson, “The Urban Crisis: The Kerner Commission Report Revisited: Health Care in the Inner City: Asking the Right Question,” *North Carolina Law Review*, vol. 71 (June 1993), p. 1647 (hereafter cited as Watson, “Health Care in the Inner City”). Watson predicts that during the next quarter century, any resulting health care legislation will focus too narrowly on containing the rising health care expenditures, and that poor, urban minorities in particular will continue to “lose their chance” to gain access to health care. Watson, “Health Care in the Inner City,” p. 1656.

⁶⁴ Randall, “Clinton’s Health Care Reform Proposal,” p. 212; Watson, “Health Care in the Inner City,” p. 1647.

⁶⁵ Watson, “A Civil Right to Health Care,” p. 127.

⁶⁶ *Ibid.*, pp. 127, 134.

⁶⁷ *Ibid.*, p. 127.

⁶⁸ *Ibid.*, pp. 127, 133.

⁶⁹ *Ibid.*, pp. 131–32.

⁷⁰ *Ibid.*, p. 131. One of the deficiencies noted by Watson is that title VI has not clearly defined prohibited discrimination in the context of health care delivery, nor has it been effective in ending the title VI discrimination caused by policies that disproportionately exclude minorities. Especially during the 1980s and early 1990s, OCR neglected its title VI health care monitoring and enforcement responsibilities. *Ibid.*; see also Watson, “Health Care in the Inner City,” p. 1669. Moreover, title VI only reaches federally assisted programs. See discussion below on ensuring civil rights protections in the health care context.

⁷¹ Watson, “A Civil Right to Health Care,” p. 131.

⁷² Title VI’s sponsors deemed its enactment an extension of Congress’ power under clause 1 of article I, section 8 (U.S. CONST. art. I, § 8, cl. 1) commonly known as the “spending clause.” See, e.g., 110 CONG. REC. 6546 (1964) (statement of Sen. Humphrey). See also Bernard Schwartz, *Statutory History of the United States: Civil Rights*, Part II (1970), p. 1019 (The power to tax includes the power to spend and, equally significant, the power to establish the conditions upon which Federal funds will be dispensed. Congress was using its power of the purse to enforce the basic guarantee of racial equality in a manner that could have the greatest impact in

creating legislation under the authority of the Constitution's commerce clause, Congress can reach any entity "affecting commerce," regardless of whether it is a federally assisted program.⁷³ In addition, while the community assurance provision of the Hill-Burton regulations includes the crucial requirement of nondiscrimination on the basis of "any other ground unrelated to an individual's need for the service or

States where patterns of discrimination had existed.) That section provides that "Congress shall have Power . . . to pay debts and provide for the common Defense and general Welfare of the United States. . . ." U.S. CONST. art. I, § 8, cl. 1. One of title VI's sponsors stated that the statute was "not a regulatory measure," but rather "an exercise of the unquestioned power of the Federal Government to 'fix the terms on which Federal funds will be disbursed.'" 110 Cong. Rec. 6529, 6546 (1964)(statement of Sen. Humphrey) (citing *Oklahoma v. Civil Service Commission*, 330 U.S. 127, 143 (1947)). See also *id.* at 7061, 7063 (statement of Sen. Pastore); *id.* at 6560, 6562 (statement of Rep. Kuchel); *id.* at 2468 (statement of Rep. Rodino); *id.* at 1613 (statement of Rep. Meader); *id.* at 1527, 2467 (statement of Rep. Celler) (citing *United States v. San Francisco*, 310 U.S. 16 (1942)). Proponents considered the principle to be simple: "Stop the discrimination, get the money; continue the discrimination, do not get the money." See, e.g., 110 CONG. REC. 1542 (1964) (statement of Rep. Lindsay).

In *Guardians Association v. Civil Service Commission*, 463 U.S. 582 (1983), the Supreme Court confirmed this extension of Congress' spending power. The Court stated that the legislative history of title VI "clearly show[ed] that Congress intended Title VI to be a typical 'contractual' spending power provision." *Id.* at 599. See also *United States v. Marion County Sch. Dist.*, 625 F.2d 607, 609 (5th Cir. 1980), *reh'g denied*, 629 F.2d 1350 (1980), *cert. denied*, 451 U.S. 910 (1981). ("[T]he United States has authority to fix the terms and conditions upon which its money allotments to state and other governmental entities should be disbursed. . . . [T]he United States may attach conditions to the grant of federal assistance, the recipient of the grant is obligated to perform the conditions, and the United States has an inherent right to sue for enforcement of the recipient's obligation in court.") (citations omitted).

⁷³ U.S. CONST. art. I, § 8, cl. 3. The commerce clause provides Congress with the authority to "regulate Commerce . . . among the several States." The clause became a significant source of congressional regulatory power over State and local activities, because its provision to regulate commerce "among" States was interpreted by the Supreme Court to include regulating activity within a State, when such activity might affect interstate commerce. See, e.g., *NLRB v. Jones & Laughlin Steel Corp.* 301 U.S. 1 (1937); *Wickard v. Filburn*, 317 U.S. 111 (1942); *United States v. Wrightwood Dairy Co.*, 315 U.S. 110 (1942); *United States v. Rock Royal Co-operative, Inc.*, 307 U.S. 533 (1939). In particular, Congress has employed the commerce clause to prevent discriminatory activities of private organizations that might impact upon interstate commerce. See, e.g., *Heart of Atlanta Motel, Inc. v. United States*, 379 U.S. 241 (1964); *Katzenbach v. McClung*, 379 U.S. 294 (1964).

the availability of the needed service in the facility,"⁷⁴ this requirement only applies to Hill-Burton funded facilities. This requirement could be extended to all health care facilities. Moreover, the scope of existing laws must be expanded by combining the protected classifications under title VI and Hill-Burton, as well as expanding on these classifications by including *all* of the following: race, color, national origin (including English proficiency level), sex, religion, age, mental or physical disability (including HIV status), sexual orientation, genetic background, geographic location of residence, method of payment, or any other factor unrelated to the need for medical care.

Second, to be more comprehensive, civil rights protections must build on existing Federal civil rights law by requiring proactive action on the part of health care service providers rather than merely requiring nondiscrimination as title VI and Hill-Burton imply. For example, under the Equal Educational Opportunities Act of 1974 (EEOA), Congress stated that "[n]o State shall deny equal educational opportunity to an individual on account of his or her race, color, sex, or national origin."⁷⁵ Therefore, failing to provide equal educational opportunity is a violation under the EEOA. This implies that covered entities must take *proactive* steps to remain in compliance with the law. With respect to one of its protected classifications, limited English proficiency, this *proactive* aspect of the EEOA's requirements was made more explicit by the statute's mandate that school districts must take "appropriate action" to help students with limited English proficiency to overcome language barriers that impede equal participation in instructional programs.⁷⁶

Similarly, under new expanded civil rights legislation, all health care providers and facilities would have an affirmative duty to take "appropriate action" to assist patients in overcoming language barriers that can hinder their access to health care services and procedures (through provisions such as interpreters to facilitate the patient-provider clinical encounters, and information translated from English into patients' respective native languages). Analogous

⁷⁴ 42 C.F.R. § 124.603 (1998).

⁷⁵ 20 U.S.C. § 1703 (1994).

⁷⁶ *Id.* at § 1703(f) (emphasis added).

to the EEOA, this new legislation would state that health care providers' failure to take "appropriate action" to overcome the language barriers that impede equal participation in health care services amounts to a denial of equal access.⁷⁷ Also analogous to the EEOA, and because it would bear a similar emphasis on proactive efforts, this new legislation might be called the "Equal Access to Health Care Services Act."

In addition to a generalized provision prohibiting discrimination and mandating proactive efforts to ensure equal access and treatment, the Equal Access to Health Care Services Act must address several more specific civil rights concerns. The means for addressing these concerns must be embedded in any civil rights legislation intended to strengthen and expand upon the civil rights provisions offered by nondiscrimination statutes in the health care context. First is the need for health care providers or insurers to record, maintain, and regularly submit to Federal, State, or local agencies, gender and race-based data on patients' access to health care facilities, health status (e.g., disease severity level, specific symptoms) at point of service, and specific medical procedures and services received. Such data should be periodically analyzed (to determine if any statistically significant disparities exist in the delivery of health care services and procedures) and reported by the recipient government agencies. Second are the communication/linguistic barriers that exist between health care providers and their customers. These barriers indicate the need for cultural- and gender-competent services that address separately the unique health care needs of minorities and women, to ensure that health care services are comprehensible, relevant, and meaningful to them. Third is the need to develop appropriate standards for determining civil rights compliance by health care practitioners and facilities, and for determining if particular health care practices have a disparate adverse impact on minorities and/or women.

The final concern relates to the significant socioeconomic barriers to health care that disproportionately affect women and minorities. As discussed earlier in this report, many minority families and female-headed households lack

adequate health care financing.⁷⁸ In addition, those that are eligible for Federal health care financing often receive discriminatory treatment based on their beneficiary status. The Equal Access to Health Care Act should explicitly prohibit discrimination based on a patient's membership in a government-funded financing program, such as medicaid, medicare, or children's health insurance program (CHIP). Further, the act should include an outreach and education component that will strengthen these programs by informing minorities and women about them. The outreach effort should be designed to integrate into the medicaid, medicare, and CHIP programs, minorities and women who were unaware of the existence of such programs or of their eligibility to participate in them.

OCR's Role in Health Care Reform

OCR must play a key role in advising Congress on the development of any civil rights provisions focused on the health care industry by offering its expertise on implementing and enforcing civil rights laws such as title VI and Hill-Burton. Barring congressional action in this area, OCR must act on its own to develop policy guidance or statements directed to recipients of Federal funds and Hill-Burton funded facilities. This guidance must fully define and operationalize the terms "equal access to quality health care," "appropriate care," and "medical necessity," as well as clearly identify all nondiscrimination requirements and any proactive action OCR deems appropriate.⁷⁹

However, OCR alone cannot create the long overdue "sea change" in the way the Federal Government views and responds to health care related civil rights concerns. Until the President, Congress, and the Secretary of HHS accept the notion that civil rights laws affording protections in the health care industry must be aggressively enforced, OCR can do little to effect the needed reforms. All branches of government must act immediately to rededicate the Nation to providing the necessary resources, civil rights expertise, and sustained high-level commitment that is required to ensure true equal access to quality health care for every American.

⁷⁸ See USCCR, *The Health Care Challenge*, Vol. I, chap. 2.

⁷⁹ See vol. II, chap. 3, for a discussion of policy guidance OCR should develop.

⁷⁷ See *id.*

Findings and Recommendations

A General Assessment

Summary

Over the past 35 years the U.S. Commission on Civil Rights has been monitoring health care access for minorities and women, focusing primarily on the important role civil rights enforcement efforts can play in providing equal access to quality health care. Although there have been some improvements in accessing health care over the last three decades, the timid and ineffectual enforcement efforts of the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) have fostered, rather than combated, the discrimination that continues to infect the Nation's health care system. This is evident in the segregation, disparate treatment, and racism experienced by African Americans, Hispanic Americans, Native Americans, Asian Americans and Pacific Islanders, and members of other minority groups, as well as in the persistent barriers to quality health care that women continue to confront.

In the United States today, there remain tremendous racial and gender disparities in access to quality health care services and health care financing, as well as in the benefits of medical research. Many of these disparities continue to plague the Nation's health care system because HHS/OCR has failed to enforce the crucial nondiscrimination provisions of the Federal civil rights laws with which it is entrusted. The HHS/OCR enforcement operation is lacking in virtually every key area of its compliance and enforcement operations. Most significantly, HHS generally has failed to undertake proactive efforts such as issuing appropriate regulations and policy guidance, allocating adequate resources for onsite systemic compliance reviews, and initiating enforcement proceedings when necessary.

Despite OCR's purported involvement in a number of departmentwide initiatives, OCR is an agency in isolation from the rest of HHS.

OCR appears to have little influence among the other agency elements. Although OCR has a relatively small budget compared with other HHS agencies, and this may be partially responsible for its poor performance, it is incumbent upon OCR staff to search for creative solutions to fiscal challenges. OCR has been especially reluctant to assume an active role in seeking innovative alternatives. In many ways, OCR has neglected to take advantage of opportunities to bolster its own enforcement efforts by cooperating with other agencies within HHS, as well as outside the Department. For example, OCR has yet to collaborate with the Office of Minority Health and Office of Women's Health, components of the Office of Public Health and Science, in order to identify and obtain information about issues relating to minorities and women in health care. Further, the office has not forged interagency agreements that outline a framework through which staff may consult with physicians within the Department in health care cases. Moreover, OCR has exerted minimal pressure on the Health Care Financing Administration (HCFA) to begin collecting racial information on medicare and medicaid patients.

Neither has OCR collaborated effectively with agencies and organizations that exist outside of HHS. For instance, the office has not maintained lasting bonds with civil rights organizations, advocacy groups, or communities to create an infrastructure that would assist OCR in carrying out its myriad of civil rights duties. Civil rights organizations and community groups could assist not only in research of health care issues, but also in educating beneficiaries of their health care rights. Advocacy groups could share in some of the investigative and legal responsibilities involved in confronting cases of systemic discrimination. Aside from declining to cooperate with nonprofit organizations, OCR has eschewed working with State recipients to develop and

monitor nondiscrimination enforcement programs at that level.

Another important aspect in which OCR has fallen short of its civil rights mandate is the dissemination of regulations and policy guidance, which is a critical function of civil rights implementation programs. Such policy development provides notice to program beneficiaries and recipients of their rights and responsibilities under Federal nondiscrimination laws, while informing OCR investigators of how to identify and eliminate discriminatory conduct. Unfortunately, OCR has issued virtually no policy guidance on title VI, title IX, or the block grant nondiscrimination provisions since 1981. This lack of productivity is of particular concern with regard to title VI, because many new forms of discrimination against minorities have emerged as the Nation has moved from “fee-for-service” medicine to managed care. Without appropriate policy guidance, neither recipients or beneficiaries of Federal funding, nor OCR investigative staff can develop a clear understanding of what constitutes discrimination by managed care and other health care organizations.

Further, OCR appears to have largely abdicated its role in compliance enforcement. OCR headquarters has declined to provide leadership to the regional offices, from assisting them in setting priorities, to offering procedural guidance for investigations. This failure has affected the regional offices’ abilities to identify and eradicate discrimination. Perhaps the most serious shortcoming in OCR headquarters’ leadership is that it has neglected to acknowledge and confront the specter of systemic discrimination. Although studies suggest that the health care industry is replete with large-scale discrimination, OCR has devoted very limited resources to identifying pattern and practice discrimination. The regional offices expend inordinate amounts of time on medicare preaward reviews, which primarily consist of desk audits. The complaint investigations that are performed are rarely expanded into full-scope compliance reviews, which implies that investigators seldom consider the extent to which the experiences of particular complainants may be shared by larger groups of patients. Regrettably, full-scope compliance reviews, which represent the predominant method of uncovering pattern and practice discrimination, are performed with relative infrequency.

Moreover, those that are performed rarely focus on systemic discrimination by managed care organizations in the Medicaid Managed Care and Medicare Plus Choice programs, which is an area of growing concern.

The deficiencies in OCR’s enforcement efforts identified throughout this report largely are the consequences of OCR’s fundamental failure to recognize the tremendous importance of its mission and to embrace fully the opportunity it has to eliminate disparities and discrimination in the health care system. Although OCR has attempted to identify noncompliance with the Nation’s civil rights laws over the years, it has failed to understand that all of its efforts have been merely reactive and in no way have they remedied the pervasive problems within the system. OCR’s failure to address these deeper, systemic problems is part of a larger deficiency within the agency, and HHS as well—OCR’s seeming inability to assert its authority within the health care system. As a result of the myopic perspective that has shaped OCR throughout its history, the agency appears unable to systematically plan and implement the kind of agencywide “redevelopment” policy that it so clearly needs.

Through this study, the Commission has found significant weaknesses in the Office for Civil Rights’ enforcement efforts. Not least among these is OCR’s failure to implement many of the recommendations indicated by the Commission in its report on title VI enforcement, which was issued more than 3 years ago. Many of the findings and recommendations below are the same or similar to those the Commission made in its title VI report. The Commission hopes that the Secretary of HHS will make every effort to address these findings and recommendations as they are intended to assist the Department in improving its civil rights enforcement efforts.

Strengthening OCR’s Civil Rights Enforcement Efforts

Finding: There is substantial evidence that discrimination in health care delivery, financing, and research continues to exist. Such evidence suggests that Federal laws designed to address inequality in health care have not been adequately enforced by Federal agencies such as the U.S. Department of Health and Human Services, Office for Civil Rights. HHS’ inability to enforce

civil rights laws and OCR's isolation from the rest of the agency, as well as the civil rights community, have resulted in a failure to remove the historical barriers to access to quality health care for women and minorities, which, in turn, has perpetuated these barriers.¹

For nearly 20 years, from 1980 to 1999, HHS has neglected its civil rights enforcement responsibilities to an almost unprecedented degree. OCR's thorough neglect of its civil rights enforcement responsibilities has been well documented not only by the Commission, but by numerous other investigative bodies, both internal to the Department and external, including the General Accounting Office, the House of Representatives' Committee on Government Operations, HHS' Office of Inspector General, and the Department's own Civil Rights Review Team. OCR's consistently weak record has resulted, in part, from the lack of commitment to civil rights enforcement within OCR and throughout the Department.

OCR's steadfast refusal to address concerns about the quality of its efforts indicates a fundamentally limited view of the role civil rights enforcement can and should play in the health care industry, a view that is deeply ingrained within the culture of HHS. What makes this disregard of recommendations for vigorous civil rights enforcement efforts particularly shameful is that HHS provides Federal assistance to medical programs and facilities that *save lives every day*. While the activities of agencies charged with protecting the rights to equality of opportunity in education and employment are matters of tremendous importance, the failure of HHS to conduct strong civil rights enforcement literally can mean the difference between *life and death*.

However, the responsibility for this shameful record does not lie with HHS alone. The rest of the Federal Government, namely Congress and the President, has failed to offer the oversight, support, and assistance to civil rights enforcement activities that HHS so desperately needs. Congress has not conducted an oversight hear-

ing on OCR's civil rights enforcement activities since 1987. Congress also has drastically reduced the agency's annual appropriation to a point where it is extremely difficult for the agency to perform its responsibilities effectively. While the President has worked with HHS to implement minority health initiatives, none of these efforts contains a strong civil rights enforcement component or attempts to develop the key role that OCR should be playing in these efforts.

Recommendation: To assist OCR in strengthening its civil rights enforcement efforts, the Federal Government must renew its commitment to title VI, title IX, the Hill-Burton Act, and the nondiscrimination provisions in block grant programs administered by HHS. All three branches of Government must play a strong and decisive role in these efforts. To begin with, 30 days from receipt of the Commission's report, HHS should develop a civil rights enforcement plan that indicates the initiatives necessary to respond to these recommendations. These plans should clearly identify the individuals responsible for carrying out the activities in the plan. In 6 months, the Secretary of HHS should submit a progress report on the implementation of the recommendations presented in this report to the Commission's assistant staff director for Civil Rights Evaluation. The progress report should identify all actions taken, proposed action plans, and timeframes for accomplishing activities that have not been completed.

In addition, HHS must commence reporting to Congress on an annual basis its civil rights enforcement efforts. This "civil rights report card" should address both the quality and quantity of OCR's activities. Therefore, it should provide OCR's accomplishments for the previous years and objectives for the next year with respect to program priorities, policy development, technical assistance, outreach, and education, as well as statistical data on the number of compliance reviews and complaint investigations conducted aggregated by region, statute, issue, and type of resolution achieved. Moreover, OCR in partnership with the Office of the Secretary should conduct a formal study of its budgetary and staffing needs in light of the nature of its workload and its strategic plan, and develop a detailed plan for what it would do with additional budgetary and staffing resources. The

¹ See chap. 1, pp. 1-15. See generally U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, Ensuring Equality, Vol. I. The Role of Governmental and Private Health Care Programs and Initiatives*, September 1999 (hereafter cited as USCCR, *The Health Care Challenge*, vol. 1), chap. 2.

plan should include accountability factors to ensure that any additional resources are used appropriately, effectively, and efficiently.

Congress also must take swift and decisive action by conducting an oversight hearing on OCR's operations. In reviewing OCR, Congress should rely on information provided by the Commission; the U.S. Department of Justice/Coordination and Review Section and other Federal agency civil rights offices; HHS operating divisions and federally assisted program offices; and State and local recipient agencies of HHS financial assistance. Congress also should seek input from grassroots community organizations and health care advocacy groups that represent the interests of health care funding recipients and, most importantly, beneficiaries of HHS-assisted programs throughout the Nation. Congress should convene an oversight task force with the responsibility of periodically reevaluating the agency's operations and issuing reports to the Committee conducting the oversight hearings until such time as the Committee is satisfied that OCR has implemented all recommended changes. Further, in its oversight role, Congress must hold annual hearings at which the Secretary of HHS and the director of OCR report on their performance and results based on an agreed-upon action plan, developed by the Secretary and the director jointly, for strengthening civil rights enforcement programs.

Congress and Federal agencies should continue to monitor OCR's civil rights enforcement activities. The Department of Justice should monitor HHS' civil rights progress and provide assistance where needed. In addition, Congress should provide increased appropriations to OCR to permit the agency to fulfill its statutory mandate and to ensure that OCR continues to improve its civil rights enforcement.

The President should issue a new Executive order clarifying HHS' authority to conduct civil rights enforcement activities and ordering HHS to develop a definition for "equal access to health care" that can be used as a standard in assessing the presence of discrimination among HHS recipients. It is essential for the President to explicitly reiterate the agency's responsibilities under civil rights statutory and regulatory laws to ensure nondiscrimination on the basis of race, color, national origin, or sex among recipients of HHS funding.

Moreover, the President should integrate civil rights policy into the domestic policy agenda by consulting formally with civil rights advisors on the effect new legislation and policies will have on civil rights in health care. To facilitate this process, the President should conduct quarterly meetings with the Secretary of HHS and the director of OCR to establish and discuss the administration's priorities for civil rights in health care. It is particularly important to include civil rights concerns in the President's health care reform agenda. For example, the President must ensure that nondiscrimination on the basis of race, color, national origin, sex, disability, and age remain a part of all health care reform proposals submitted to Congress.

To ensure a genuine strengthening of HHS' civil rights enforcement program, the President and the Secretary of Health and Human Services should issue a joint statement reinforcing their commitment to the enforcement of civil rights statutes, particularly title VI and title IX, in the health care context. This should be accompanied by corresponding annual increases in funding for civil rights enforcement at HHS, justified by detailed analyses of the effect of other civil rights responsibilities on OCR's enforcement of title VI and title IX.

Finding: OCR regions do not maintain information on the names or the total number of HHS recipients within the region,² nor does OCR have a standard or systematic approach to selecting and conducting onsite compliance reviews.

Recommendation: Information on the universe of HHS funding recipients is crucial to ensuring civil rights compliance. OCR should maintain this information and use it in planning compliance reviews. OCR should have a standard approach to compliance reviews such that all major civil rights provisions are included in a review and all recipients have an equal chance at being reviewed. For example, OCR should ensure that all recipients are reviewed on a rotating basis, perhaps every 3 years. Lacking resources to review every recipient, OCR should select a sample of recipients to be reviewed. OCR should contact all recipients and inform them of the systematic approach it will be taking in conducting compliance reviews. In this manner, recipients will be notified that OCR takes its civil

² See chap. 4, p. 152.

rights enforcement requirements seriously and that recipients will be reviewed for their adherence to civil rights laws.

Departmentwide Support for OCR's Civil Rights Enforcement Efforts

Finding: Civil rights enforcement at the Department of Health and Human Services lacks direction because both the Secretary and the director of OCR have failed to provide appropriate leadership for and the necessary emphasis on civil rights enforcement activities at HHS. As a result, civil rights enforcement is neither a top priority nor an integral part of HHS' primary mission planning. The Secretary has delegated authority to OCR to enforce civil rights laws and programs, but has failed to monitor and assess important aspects of civil rights enforcement, such as budget, staff resources, compliance reviews, and complaint investigations. As a direct consequence, civil rights enforcement at the departmental level and within OCR itself is grossly underfunded and, equally troubling, accorded very little status and almost no emphasis among the Department's other agencies and the Secretary herself.³

Recommendation: HHS must make civil rights enforcement a top priority. The Secretary of Health and Human Services must ensure that civil rights components are incorporated into all HHS programs. The Secretary must give OCR the power to provide guidance to all HHS programs and operating divisions. OCR must actively participate in planning for new programs and provide technical assistance and guidance to HHS staff. In addition, HHS must be committed to eradicating disparities in access to quality health care. This can only be done with the assistance and guidance of OCR staff.

The Secretary, in partnership with the director of OCR, should develop an action plan to focus and strengthen OCR's civil rights enforcement efforts. This action plan should: (1) require the development of a standing Civil Rights Review Team to evaluate OCR's efforts on a periodic basis; (2) recommend, develop, and disseminate departmental policies on implementing civil rights statutes; (3) offer assistance to OCR in more clearly defining and more aggressively pursuing its own priorities; and (4) create a

model plan for the Secretary to use in making the strongest possible case to Congress for significantly increased civil rights enforcement funding. Such a model plan should include a marshaling of statistical and anecdotal evidence showing the need for increased funding and demonstrating how such funding could be used to more effectively implement civil rights objectives.

Publicizing Nondiscrimination Laws

Finding: The Commission's review of OCR's letters of finding revealed very few complaints or compliance reviews based on title VI and race issues, with the exception of issues relating to limited English proficiency. However, the scarcity of race-based complaints does not necessarily indicate the absence of discrimination on the basis of race and/or ethnicity; discrimination often is very subtle and patients are often unaware that they have been discriminated against.⁴

Recommendation: HHS, particularly OCR, must initiate a campaign to ensure that information is made available to all citizens concerning their right to have equal access to quality health care. OCR should require all health care facilities receiving HHS funds to provide information to their patients concerning their civil rights in the health care context and how to file a complaint if they believe they have been discriminated against. In addition, OCR must reach out to community organizations and individuals who are likely to have experienced discrimination in the health care context.

A key method of providing information to the public is through the media. Congress should appropriate funds to OCR for publicizing the importance of receiving quality health care. Such a media campaign should focus on preventive care as well as ensuring nondiscrimination in the provision of health care services. The public should be informed of the importance of quality health care and what their rights are. OCR should ensure that all citizens have information on how to contact OCR to file a complaint if they have experienced discrimination.

In addition to reaching out to the public, OCR must educate health care providers concerning civil rights requirements and cultural competency. Not only must health professionals pro-

³ See generally chaps. 1, 2, 3, 4.

⁴ See chap. 1, p. 13. See generally chap. 4.

vide treatment, but they must provide treatment in a nondiscriminatory manner, which includes being sensitive to the languages, cultures, and traditions of various groups. OCR must partner with health care organizations, community organizations, and civil rights organizations to ensure that information on equal access to quality health care is disseminated to all segments of society. Such organizations can also provide OCR with valuable information on the health needs of different groups, as well as problems encountered by the health care industry in ensuring equal access to quality health care. By working in conjunction with the many facets of the health care industry, OCR can better understand health care issues from both the patients' and providers' perspectives and, thus, be able to assist funding recipients and beneficiaries in working together to ensure equal access to quality health care.

Addressing Lack of Adequate Health Care Access for the Uninsured

Finding: A basic foundation of the Nation's health care system is the ability to pay for services as the principal determinant of access to health care. It is intuitive that in such a system, those with the least ability to pay will be the least served. As a result, members of racial/ethnic minority groups, who are a disproportionately high percentage of the uninsured, experience inadequate access to health care with far greater incidence than their white counterparts. Although the system is not intentionally designed to deprive individuals of equality of opportunity based on race or ethnicity, this has been one of its unfortunate byproducts.⁵

Recommendation: Congress must act immediately and decisively to address the failure of the Nation's health care system to provide adequate care to those without coverage. Congress should enact at least two pieces of legislation. First, Congress should revive funding for the Hill-Burton Act for the creation of medical centers and other services designed specifically to provide quality care to the poor and underserved.

Second, Congress should ensure that *all* protected classes are covered in block grant legisla-

tion. All States and subrecipients of block grant funds and other Federal funding must ensure that title VI, title IX, and other civil rights laws are incorporated into such programs. Congress must acknowledge the importance of civil rights enforcement and compliance efforts in all programs, but especially health-related programs.

Congress also must take action to ensure that health care providers, particularly recipients of HHS and other Federal funding, do not discriminate in the provision of health services. Any legislation relating to access to quality health care, health care financing, or health care research must include authority for OCR to monitor the health care industry for civil rights compliance. Congress must make clear to the public that eliminating health disparities in this country requires strong enforcement of civil rights legislation.

OCR's Performance Relative to Other Civil Rights Enforcement Agencies

Finding: In evaluating OCR's civil rights enforcement efforts with respect to title VI, title IX, the community assurance provisions of the Hill-Burton Act, and the nondiscrimination provisions in block grant statutes, the Commission has found significant weaknesses in every area of OCR's operations, including complaints and compliance review investigations, rulemaking, and policy development. OCR's efforts are particularly ineffective when compared with some of the more sophisticated civil rights enforcement programs the Commission has evaluated in recent years, especially those of the U.S. Department of Education (DOEd) Office for Civil Rights and the U.S. Equal Employment Opportunity Commission (EEOC). In many ways, EEOC's enforcement of title I of the Americans with Disabilities Act (ADA) can serve as a model program for implementing and enforcing civil rights laws.⁶

Recommendation: The Secretary of HHS should inform both DOEd and EEOC that OCR is requesting informal guidance on ways to reinvigorate its civil rights enforcement efforts particularly with regard to title VI. OCR should appoint liaisons to both agencies and a task force to begin reviewing specific areas of its operations. OCR should focus on the efforts EEOC has undertaken on title I of the ADA. OCR should focus

⁵ See generally chap. 6, and USCCR, *The Health Care Challenge*, vol. I, chap. 2.

⁶ See generally chaps. 3, 4.

on the technical assistance, policy development, and case processing elements of EEOC's ADA enforcement program. In particular, OCR should review EEOC's title I technical assistance manual and its title I compliance manual to help in developing its technical assistance and case processing activities. Also, OCR should model its policy development after EEOC's ADA policy development, which has been vigorous and comprehensive during the past 7 years. EEOC's policy guidances have addressed fundamental principles, such as statutory definitions and elements necessary to prove discrimination as well as specific enforcement-related issues.

HHS' Failure to Respond to the Commission's Recommendations

Finding: For 35 years, HHS and its predecessor agency, the Department of Health, Education, and Welfare (HEW), have condoned policies and practices resulting in discrimination against minorities and women in health care. In many ways, segregation, disparate treatment, and racism continue to infect the Nation's health care system. HHS has pursued a policy of excellence in health care for white Americans by investing in programs and scientific research that discriminate against women and minorities. HHS essentially has condoned the exclusion of women and minorities from health care services, financing, and research by implementing an inadequate civil rights program and ignoring critical recommendations concerning its civil rights enforcement program. The Commission, the HHS Office of Inspector General, and the HHS Civil Rights Review Team have offered many recommendations for improving civil rights enforcement at HHS. However, failure to implement these recommendations has resulted in failure of the Federal Government to meet its goals of ensuring nondiscrimination and equal access to health care for minorities and women.⁷

Recommendation: OCR must aggressively enforce civil rights statutes in the health care context. This can be done through the following methods: (1) developing policy in key areas such as medical school admissions, managed care, and clinical trials; (2) expanding its civil rights enforcement program to include more detailed, full-scope compliance reviews, more effective

monitoring of State recipients and subrecipients of HHS funding, improved technical assistance, and improved data collection strategies; and (3) partnering with HHS operating divisions and other organizations that have programs in place to eliminate disparities in health care.

In addition, the Secretary of HHS must ensure that OCR has the appropriate resources (including staff, budget, training, and computer technology) to carry out its mission. OCR must have a strong presence both within and outside of HHS. Civil rights considerations must be incorporated into all HHS programs, and all citizens must be made aware of their civil rights in health care. HHS/OCR needs to examine its civil rights enforcement program and find a way to make it a strong, proactive force for ensuring civil rights compliance among the many HHS funding recipients across the country.

Confronting Discrimination in Health Care: 2000 and Beyond

Finding: There is little doubt that racial, ethnic, and gender disparities in health care will persist in the 21st century unless Federal enforcement of civil rights laws is strengthened. Structural changes in the health care system must occur before it can serve everyone equally. It is beyond the scope of this report to address these changes. However, a crucial component of any major changes to the U.S. health care system must be to ensure that it is free of discrimination against minorities and women. We have a long way to go to reach this goal. Nonetheless, we can strive to change individual perceptions and energize institutions that have become inured to the disparities and acquiescent to the demands of the business interests pervasive in our health care system. Discrimination will continue in the health care industry if individuals and institutions continue to be profit motivated and self-interested. However, the ultimate outcome of disparities in health care that we cannot forget is the chronic ill-health and untimely deaths of those who receive inadequate, inequitably distributed health care.⁸

Recommendation: The Federal Government must act swiftly and decisively to eradicate the inequities in access to quality health care.

⁷ See generally chap. 1.

⁸ See generally chap. 6, and USCCR, *The Health Care Challenge*, vol. I, chaps. 1, 2, 3, 4.

Through legislation, directives to Federal agencies, and partnerships with private entities, the Government should make the health care system available to everyone. To do so, Congress must better fund OCR, and HHS must focus on bringing OCR into the fold and better utilize civil rights enforcement to address discrimination in health care. OCR itself should begin the process of reinvigorating its entire enforcement program, through all means necessary.

OCR cannot eliminate health care disparities by itself. Congress must provide OCR the necessary resources and funding to implement effective civil rights compliance activities. Further, OCR must be given appropriate authority by the Secretary to become more proactively involved in health care programs funded by HHS. HHS operating divisions must enlist the assistance of OCR in planning programs and initiatives. OCR must be involved at all levels of the planning processes within HHS to ensure that civil rights matters are appropriately addressed.

It is crucial that Congress, the President, the Secretary of HHS, and the Surgeon General acknowledge the need for civil rights enforcement and monitoring in Federal programs. Together with OCR, the administration must develop a plan to eradicate disparities and discrimination within the health care system which should include initiatives and programs that incorporate civil rights. Congress and the President must assure that appropriate, quality health care is provided to all without regard to race, color, ethnicity, national origin (including English proficiency level), sex, religion, age, mental or physical disability (including HIV status), sexual orientation, genetic background, geographic location of residence, ability to pay, or any other factor unrelated to the need for medical care. This should encompass equitable and culturally sensitive care, affordable care, and inclusion in health research and clinical trials.

Chapter 2. Organization and Administration of the U.S. Department of Health and Human Services

Summary

The organization and administration of the civil rights component of HHS betray a subtle contempt for Congress' legislative mandate of ensuring equal participation in HHS-funded programs in general, and in health care pro-

grams in particular. The Department appears to have dissociated itself from OCR to a significant degree, as evidenced by the numerous ways in which it has undermined OCR's efforts. First, while the budget for the Department has increased steadily, OCR funds have fluctuated at around \$20 million since 1981, failing even to keep up with inflation. In addition, the Department's 1997 Strategic Plan contains little reference to OCR. It mentions the eradication of discrimination only in passing, and makes no reference to OCR's important role as the enforcer of civil rights in HHS programs.

The Department's apparent disregard for OCR and its civil rights mandate has had the effect of denying the office the status and influence required to perform its civil rights duties. HHS leadership has not facilitated collaboration and communication among OCR and other HHS components whose operations relate to women's and minorities' issues. For instance, the Office of the Secretary has not prompted or supported OCR in cooperating with the operating divisions to ensure that their programs remain free of discrimination. Neither has the Office of the Secretary fostered coordinated efforts among OCR and the staff divisions of the Department. For instance, the Secretary has not required the Office of Minority Health or the Office on Women's Health, components of the Office of Public Health and Science, to collaborate with OCR in developing policy for implementing the numerous minority and women's health care initiatives at the departmental level. The absence of cooperation among OCR and the research offices in all likelihood has resulted in a waste of resources both on the part of OCR and by the scientific research and program communities, as they have worked in isolation from one another in attempting to identify the barriers faced by these groups in gaining access to quality health care.

While, overall, the Commission has found that the organizational structure of OCR is adequate for enforcing civil rights laws, major aspects of civil rights implementation have failed to garner an appropriate measure of OCR's attention. OCR headquarters has divisions dedicated to quality assurance, policy development, and technical assistance, but efforts in these areas have born little fruit. For example, headquarters staff have not indicated that they conduct any systematic review of the regions' case

closure materials, or that they conduct onsite quality assurance. With the exception of recent work to develop policy guidance documents in three areas, OCR has disseminated almost no policy guidance since 1981. Neither has headquarters OCR provided significant leadership to regional offices in implementing technical assistance programs. The failure on the part of headquarters OCR to provide quality assurance, policy guidance, and technical assistance support has hampered the regional staff's understanding of discrimination issues, and has resulted in an absence of standardized procedures for quality assurance and technical assistance at the regional level. Further, it appears that headquarters OCR provides very little guidance to the regions in their day-to-day operations, such as complaint intake, which also lacks standard procedure. There also is inadequate communication among the regional offices and almost no coordination on enforcement activities such as compliance reviews.

Such deficiencies are magnified by severe budget and staffing limitations. OCR's FY 1999 budget is \$20.6 million, which is only 0.0054 percent of the total HHS budget. This tiny fraction appropriated to OCR is just one of the many ways that OCR's low-level status and isolation within HHS are apparent. Headquarters staff assert that the lack of resources has placed OCR at a distinct disadvantage, making it difficult for the agency to accomplish its mission. For example, OCR claims it has not had adequate resources to hire and train staff. However, it must be noted that headquarters OCR has assigned a significant amount of resources to offices that have displayed only modest productivity. For example, two offices, the Policy and Special Projects Staff and the Division of Program Development and Training in the Office of Program Operations, each employs nine full-time staff members. These offices are responsible for developing policy and procedural guidance. However, as stated above, OCR has produced few policy guidance and procedural guidance documents since 1981.

The absence of fiscal and administrative support from the Office of the Secretary, combined failure of OCR staff to meet the civil rights implementation challenges that confront it, have contributed to OCR's inability to implement title VI, title IX, the Hill-Burton Act, and the nondis-

crimination provisions of the HHS-funded block grants. Many of OCR's activities have been compromised, including the development of policy guidance on substantive civil rights issues, investigative and compliance review procedures, and technical assistance.

Mission and Responsibilities of OCR

Finding: As the Federal agency solely responsible for health care concerns in the Nation, HHS is responsible for ensuring that all Americans are afforded equal access to quality health care, free of discrimination. In addition to responding to complaints of discrimination, OCR is responsible for reviewing policies and practices with potential discriminatory impact on women and minorities, such as medical redlining, excessive wait times for care, unequal access to emergency care, requiring deposits before providing care, and lack of continuity of care. Further, OCR is responsible for eliminating overt discrimination, denial of services, and disparities in health care that can endanger the lives of patients, particularly women and minorities. However, as this report has shown, HHS is deficient in several areas of civil rights enforcement. There are a variety of civil rights enforcement activities that OCR does not perform very well. Title VI policy development is seriously lacking, compliance reviews focus on narrow issues, and complaint investigations are often inadequate. Further, headquarters OCR appears to provide little oversight to regions in their day-to-day operations and does not coordinate activities across the regions. Similarly, there is a division of authority between the Civil Rights Division of the Office for General Counsel and OCR, resulting in little proactive work being done by the OGC Civil Rights Division.⁹

Recommendation: OCR must ensure that sufficient staff resources are applied to policy development, compliance reviews, and adequate complaints investigations. Further, OCR headquarters must become more proactively involved in the activities of the regions by coordinating compliance reviews, providing feedback, and overseeing technical assistance activities.

OCR should have a full-time staff devoted to the development of policy guidance. These staff members, situated in the Policy and Special

⁹ See chap. 2, pp. 18-19.

Projects Staff (PSPS), should have expertise in health care, social science, and civil rights and health care law. Legal staff from the Office of General Counsel, Civil Rights Division, should be permanently reassigned to PSPS for policy development. PSPS staff with expertise in social science and health care issues should conduct research on issues affecting health care and work with legal staff to ensure that appropriate guidance is developed for both OCR staff and recipients of HHS funding.

In addition, staff in OCR headquarters should be more proactive in coordinating the work of the regions in regards to compliance reviews and technical assistance, outreach, and education. Investigative methods and outreach materials should be shared among the regions to ensure that the most effective practices are being followed by all regions, and to ensure that there is no duplication of efforts.

Finding: There may be instances over which HHS/OCR and the Department of Education (DOEd) Office for Civil Rights (OCR) both have jurisdiction. However, there are no clear guidelines on handling title IX cases in the health care context.¹⁰

Recommendation: HHS and the Department of Education need to work together to clarify jurisdiction and prepare policy guidance on title IX. In particular, HHS/OCR and DOEd should enter into a memorandum of understanding that specifies which aspects of title IX enforcement in the health care context each is responsible for handling. HHS and DOEd should develop a system for referring complaints to each other, as appropriate, and should work together in conducting compliance reviews and complaints investigations, as needed.

In addition, HHS/OCR should include title IX issues in compliance reviews. Overall, OCR should conduct full-scale compliance reviews of all HHS funding recipients. Such full-scale compliance reviews should encompass all civil rights statutes over which OCR has jurisdiction, including title IX. Absent resources for full-scale compliance reviews of all recipients, OCR should begin to address title IX issues, such as ensuring women have equal access to health care research positions, that it has neglected in the past.

Finding: Headquarters OCR has no direct authority over HHS operating divisions, and thus does not get involved in civil rights issues within the operating divisions unless requested. There is no written policy directing operating divisions to forward complaints to OCR, which could lead to a complaint not being handled properly or investigated in a timely manner.¹¹

Recommendation: In a formal agency policy directive, the Secretary should state that operating divisions are required to forward complaints of discrimination to OCR for investigation. OCR should follow this with a memorandum to all operating division heads and regional directors providing explicit instruction as to whom complaints should be sent in each region. In addition, OCR should provide basic information to the operating divisions on the process for investigating complaints. The Secretary also must ensure that OCR has the appropriate authority to become involved in HHS programs to ensure civil rights enforcement is incorporated into all aspects of HHS' operations.

Finding: Compliance reviews can be limited-scope compliance reviews (focusing on a particular issue) or full-scope compliance reviews (usually covering all the classifications and related issues within a statute). Pregrant reviews focus on the civil rights program of applicants when they apply for funding for medicare programs. OCR, however, does not conduct preaward reviews of other applicants, which is a serious omission. More proactive monitoring and interaction with applicants and recipients can prevent unlawful discrimination, help increase awareness and understanding of civil rights issues, and would make HHS more familiar with the policies and practices of applicants and recipients.¹²

Recommendation: OCR should implement a comprehensive pre- and postaward compliance review program. *All* applicants must be reviewed to ascertain any potential civil rights violations. In addition, *all* recipients of HHS funding must be reviewed on a regular basis. OCR should ensure that recipients receive a thorough, full-scale compliance review on a systematic schedule, such as once every 3 years. Such reviews should encompass all applicable civil rights statutes and

¹⁰ See chap. 2, pp. 17–18, and chap. 3, pp. 60–62.

¹¹ See chap. 2, pp. 26–27.

¹² See chap. 4, pp. 155–171.

should include mandatory onsite interviews and factfinding.

Organization of Civil Rights Responsibilities at HHS

Finding: In its 1996 report on title VI enforcement, the Commission found that, generally, the organizational structure of HHS' external civil rights enforcement program is adequate for title VI enforcement. The director of OCR reports directly to the Secretary of HHS. The director also has direct authority over all staff conducting title VI enforcement activities, both in the headquarters and regional offices. This organization enables the director of OCR to influence HHS' policy decisions affecting external civil rights enforcement. It also enables OCR to directly manage, and thereby ensure uniformity, in the execution of HHS' title VI enforcement procedures. In addition, OCR is not responsible for HHS' internal civil rights responsibilities. This ensures that agency equal opportunity responsibilities do not compromise external equal opportunity responsibilities.

Although the organization of OCR is sufficient to accomplish its civil rights enforcement responsibilities, there are several functions that are neglected within its organizational scheme. For example, OCR does not have an effective and proactive policy and planning unit for civil rights enforcement. Few policy guidances have been written in the past 5 years, and there is no systematic mechanism for issuing policy guidance on a regular basis. Much of the work of the Policy and Special Projects Staff appears to be outdated and many documents are in formats that render information difficult to use. The Policy and Special Projects Staff prepares a weekly information report that is sent to OCR senior staff and regional managers, but there is no accompanying explanation of the attached documents or discussion of their importance to OCR. Further, PSPS has produced no new publications since the early 1990s, when fact sheets were developed on each of OCR's civil rights authorities. Another product of the Policy and Special Projects Staff is the compendium of OCR's title VI policy documents. This collection includes copies of memoranda and letters concerning civil rights issues. The documents are indexed in several ways (subjects, civil rights issue, program facility type, regulation citation)

which facilitates use of the many documents. However, these documents are often outdated and poorly copied.¹³

Recommendation: Policy documents should be written as usable policy documents on a continuing basis. This information must be organized and made available in a format that is easy for the general public to use and understand. Policies and issues should be summarized so that recipients and individuals clearly understand their rights and responsibilities under title VI, Hill-Burton, title IX, and other antidiscrimination laws and regulations. Further, weekly information reports need to be presented in a usable format. Summaries of the civil rights issues and positions in these documents, with citations to the actual documents, would also be useful. In addition, the Policy and Special Projects Staff must develop publications, in coordination with the Office of Program Operations, to provide outreach, education, and technical assistance.

Although OCR's organizational structure is generally sufficient to facilitate title VI enforcement in HHS-assisted programs, it could be improved. First, OCR headquarters should acquire legal staff, independent of the Office of the General Counsel, to provide the legal guidance and interpretation and regulatory development requisite to title VI enforcement. Second, OCR should establish an effective and proactive policy and planning unit to provide overall guidance to the regional and operating staff on title VI enforcement.

Finding: Although there is a Quality Assurance and Internal Control Division with four employees, there have been no systematic formal quality assurance reviews since before 1993, and there is no standard review of letters of finding. However, headquarters periodically holds case consultation meetings (via telephone) with regional managers. Absent a quality assurance program, with a systematic review of case findings and legal sufficiency review of letters of finding, OCR cannot ensure that cases are being closed properly.¹⁴

Recommendation: OCR headquarters staff in the Quality Assurance and Internal Control Division must conduct systematic quality assurance reviews of letters of finding and other case closure documents to ensure that OCR staff con-

¹³ See chap. 2, pp. 19-23. See also chap. 3.

¹⁴ See chap. 2, pp. 22.

duct sound investigations and to ensure that the findings are supported by the investigation. At a minimum, a sample of case closure documents should be reviewed monthly. Increased headquarters involvement in the investigative process will also ensure greater familiarity of headquarters staff with the activities of the regional offices.

Finding: According to the regional staff, communication between headquarters and the regions is slow, inadequate, and nonresponsive; basically, the headquarters staff lack sufficient knowledge of the issues to be of assistance to the investigators. Regional staff also identified deficiencies in communication between OCR and other Federal agencies.¹⁵

Recommendation: The director of OCR should assign headquarters staff the responsibility for interacting with regional staff on a consistent basis. Headquarters staff, perhaps in the Policy and Special Projects Staff, who have knowledge of current issues in health care and civil rights, should be available to provide assistance to regional staff throughout investigations and compliance reviews. In addition, staff in the Office of Program Operations should be trained in the latest investigative techniques and theories of discrimination in the health care context, and should be available to assist in investigations and compliance reviews, as needed.

To improve communication between headquarters and regional offices, OCR should strengthen its weekly information reports to provide more detailed information and discussion of how such information affects the work of OCR. Further, OCR should develop a newsletter that provides information on regional activities, or more widely distribute significant activities reports. Much of this information could be transmitted to regional staff via e-mail. Regular conference calls among regional staff and between regional offices and headquarters is also vitally important. OCR must ensure that staff at all levels have open communication with headquarters offices.

Finding: Most regional offices are not organized into separate divisions as is headquarters OCR, nor do they specialize their functions. For example, there are no staff in either headquarters or the regions who focus specifically on certain laws or classifications, such as title VI,

gender issues, or Native American issues. Region II staff stated that when the region had more resources there were more divisions, including a quality assurance division and an outreach unit. However, currently, the regions do not have enough resources to specialize their functions.¹⁶

Recommendation: OCR should organize the regional office across programmatic lines to ensure maximum use of staff and budgetary resources. For example, regional offices should be organized to include divisions responsible for quality assurance, technical assistance, investigations, preaward reviews, and compliance reviews. OCR should also ensure that staff specialize in different areas of civil rights enforcement, such as title VI, title IX, managed care, clinical research, and outreach.

Further, in both headquarters and the regions, OCR should designate individual staff members to serve as subject-matter experts on specific protected classifications, such as race, color, and national origin. OCR should assign staff members to develop expertise on current issues affecting particular communities. For example, OCR should ensure that there are individual OCR experts on African American, Native American, Latino, Asian American, and women's issues. These experts should familiarize themselves with issues relevant to particular minorities by developing contacts and working relationships with key civil rights organizations representing those groups. Staff members, therefore, should work with organizations such as the National Council of La Raza, National Association for the Advancement of Colored People (NAACP), National Organization of Women (NOW), and the Urban League. Based on these contacts, OCR staff members should obtain the latest reports issued by these groups and monitor any lobbying or legislative activities in which these groups are involved. Staff members should use the expert knowledge they develop to assist OCR in site selection for compliance reviews; outreach and education activities, such as conferences and forums; and any issues affecting departmentwide initiatives relating to these groups. In addition, OCR staff members should work with the operating divisions and State and local recipients on information sharing projects.

¹⁵ See chap. 2, pp. 24–25, 49.

¹⁶ See chap. 2, p. 24.

OCR needs sufficient staff in order to tailor its operations in such a manner. The director of OCR must initiate a needs assessment to document the additional resources needed to specialize regional staff across programmatic lines. Such an assessment should be used as the basis of requests to the Secretary and Congress for additional funding and staffing. OCR must document its need for additional resources by demonstrating the additional work that can be accomplished through increased staff and budgetary resources.

Finding: Overall, regional offices have little interaction with one another. Regional managers sometimes communicate with each other, and headquarters has teleconferences with the regional managers. However, in regards to compliance reviews, complaint investigations, training, outreach, education, and technical assistance, there is little interaction between the regions. Further, headquarters OCR oversees the regional offices, but appears to give them little guidance. For example, there is no formal method of directing technical assistance efforts in the regions; OCR does not specify standard procedures for complaint intake and investigation; and OCR does not get involved to a great extent in writing letters of finding, developing corrective action agreements, or conducting compliance reviews. Further, while the director of OCR identifies national priorities for enforcement, regional offices are free to fashion their own compliance and outreach programs. Regions may develop their own investigation and intake procedures, conduct reviews as they see fit, and perform their own outreach and technical assistance.

Headquarters appears to have little control over the regions. OCR headquarters has minimal interaction with equal opportunity specialists (EOS) and attorneys in the regions. OPO appears to be more reactive than proactive. The office fails to maintain and implement annual training plans for its staff. Regional offices conduct outreach, yet outreach is not coordinated among the regions by the headquarters office. Further, OPO provides little guidance and oversight concerning compliance reviews and complaint investigations.¹⁷

Recommendation: It is necessary that a central office coordinate regional offices to en-

sure that the "best practices" developed in the field are followed by all regions. OCR headquarters must facilitate routine and regular communication among OCR headquarters, the regional offices, and other HHS components. A liaison at headquarters should be assigned to each regional office. There should be regular meetings and visits by regional staff to headquarters to exchange information and ideas about workload, activities, and problems.

Further, headquarters OCR needs to become more involved with the daily workings of the regional offices so that issues and projects can be coordinated among the offices and efforts will not be duplicated. In particular, headquarters should coordinate outreach, education, technical assistance, and staff training efforts so that resources, such as training materials, policy documents, and fact sheets, can be shared. In addition, headquarters staff should be more involved in compliance reviews and investigations to ensure that sound methods are being used and that successful strategies developed in one region can be shared by all the regions.

Communication among the regional offices and between the regions and headquarters needs to be improved. Regular, perhaps bi-weekly, conference calls should be held between headquarters staff and key regional staff, such as regional managers and supervisory equal opportunity specialists. In addition, regional staff specializing in certain areas, such as title VI issues or technical assistance, should have conference calls and meetings with their counterparts in other regional offices, as well as headquarters staff with the same expertise. Regular communication in the form of policy guidances, weekly information reports, and other correspondence also will increase the flow of information from headquarters to the regions.

OCR needs to provide more oversight and guidance. OCR should review each region's procedures and develop standards for handling complaint intake and investigation, compliance reviews, and other enforcement activities. In addition, OCR should work with regions to develop and identify the most effective and efficient ways of providing technical assistance and outreach to recipients and beneficiaries. In other words, OCR should coordinate the activities of the regional offices and standardize procedures

¹⁷ See chap. 2, pp. 24-25.

and activities, as appropriate, across the country, relying on regional input.

Finding: The Civil Rights Division of the HHS Office of the General Counsel (OGC) provides legal support and advice to OCR. Even though OCR provides funding for the salaries of attorneys in OGC who service OCR, Civil Rights Division staff report directly to the general counsel, not to the director of OCR. According to the associate general counsel for Civil Rights, it has not been established who has formal authority over the Civil Rights Division. This is a serious oversight, resulting in the potential confusion of jurisdiction, and rendering the division devoid of the ability to take proactive steps in working with other offices within OCR.

OGC represents the legal interests of the agency as a whole and not solely the compliance requirements embedded in the nondiscrimination provisions of civil rights laws. Because OCR takes guidance and direction from OGC on legal, policy, and administrative matters relating to the statutes it enforces, OCR does not have complete control over the administrative process for resolving compliance-related issues. Ultimately, however, OCR is responsible for ensuring compliance with the civil rights statutes it enforces. This organizational scheme deprives OCR the authority to make final determinations on whether civil rights violations have occurred and to identify the appropriate response to remedy noncompliance.

For the most part, the Civil Rights Division plays primarily a reactive role, assisting OCR only when needed. The Civil Rights Division does not initiate projects or inquiries, nor does it provide great input for the annual operating plans of the regional offices. This reactive approach does not fully employ the legal skills available to OCR; OGC civil rights staff do not actively develop policy documents, provide technical assistance, or get involved in compliance reviews and complaint investigations. This appears to be a misuse of a valuable legal resource.¹⁸

Recommendation: The Secretary should clearly define the role of the Civil Rights Division and the division should be assigned proactive civil rights duties. In addition, the associate general counsel for Civil Rights should work in conjunction with the director of OCR to ensure

civil rights laws and regulations are enforced, technical assistance is provided to HHS offices and recipients, and compliance reviews and investigations are handled in an effective and efficient manner. The Civil Rights Division should provide assistance and support to OCR when needed, but OCR should have its own legal office and should not be bound by OGC in its interpretation and implementation of civil rights laws. To ensure that the administrative process under title VI and title IX is not influenced by agency elements outside of OCR, such as OGC, but is solely controlled by OCR, as the appropriate and autonomous authority to ensure nondiscrimination and enforce compliance requirements of civil rights laws, OCR should have its own “inhouse” legal arm to provide guidance.

Workload and Staffing

Finding: It is unclear why certain divisions of OCR are well-staffed, compared with others. For example, there are nine staff members on the Policy and Special Projects Staff, yet little is done in the area of policy development. Similarly, the Program Development and Training Division has nine staff members. The division is responsible for designing and conducting training for all OCR personnel, including the regional offices, yet there have been few centralized training efforts in recent years, reportedly due to lack of funds. However, despite the fact that outreach is an important part of OCR’s mission, there are only two staff members in the Voluntary Compliance and Outreach Division. Given its current staffing level, an uneven distribution of staff hinders OCR’s efforts. Thus, it is crucial that OCR find ways to use its staff as effectively as possible.

The regional offices also suffer from limited staffing and resources. The distribution of staff members among the offices is uneven, contributing to OCR’s difficulties in enforcing civil rights laws. The number of staff persons in each regional office fluctuates greatly—from nine staff members (in Region II) to 22 staff members (in Region VI).

Nonetheless, although OCR maintains that it has experienced a devastating decline in the number of employees, it has failed to appropriately account for the effect the decline has had on the operations of OCR. Lacking a detailed analysis of the repercussions of insufficient staff,

¹⁸ See chap. 2, p. 26.

OCR will find it difficult to convince Congress that additional staff are needed.¹⁹

Recommendation: Additional staff are needed if OCR is to carry out a vigorous civil rights program. OCR must have sufficient staff, particularly in the regions, to conduct comprehensive onsite compliance reviews and complaint investigations, as well as to conduct outreach, education, and technical assistance. Further, additional staff are needed for developing appropriate policy guidance and training for civil rights staff and program administrators.

OCR should evaluate the distribution of staff and ways that the assignment of staff will produce the most effective and efficient use of resources to address the workload. For example, it may be more cost effective to redistribute resources and increase staff to enhance the use of technical assistance if such efforts will affect other operations, such as encouraging voluntary compliance, improving the efficiency of compliance reviews, and decreasing the amount of discriminatory complaints that are filed.

OCR also must evaluate the effect insufficient staff has on its ability to accomplish its mission. OCR should prepare a detailed analysis of the number of staff required to appropriately carry out full-scale compliance reviews, complete investigations in a timely manner, and provide outreach, technical assistance, and education to HHS recipients, current and potential program beneficiaries, advocacy groups, and other members of the public.

OCR's History and Past Performance

Finding: Several internal reviews of OCR activities have revealed deficiencies in OCR's operations. For example, in the early 1990s, the HHS Civil Rights Review Team found that, because the focus of HEW's Office for Civil Rights had been on education, the HHS/OCR lacked policies and procedures related to health care. Further, a 1992 HHS Office of Inspector General (OIG) review of OCR's Hill-Burton program found that OCR had limited authority to enforce the Hill-Burton regulations and that no formal or uniform procedures were in place to followup on corrective action agreements and to ensure that facilities were in compliance. The OIG recommended that OCR develop a system to moni-

tor compliance agreements, conduct unannounced visits of Hill-Burton facilities to review their compliance with the law, and determine whether regional guides and methods can be shared throughout all regional offices. In addition, the OIG recommended that OCR seek legislative authority that would allow it to take administrative action against facilities that fail to comply with the Hill-Burton Act. However, little action has been taken to address the recommendations of these reports.²⁰

Similarly, in its 1996 report on Federal title VI enforcement, the Commission found that HHS still had not published title VI guidelines and had issued few policy directives. In addition, the Commission noted that OCR continued to lack a comprehensive preaward review process, conducted few postaward desk audit reviews and comprehensive onsite compliance reviews, had an increasing complaint backlog, and lacked a comprehensive system for monitoring corrective action agreements. Further, the Commission recommended that OCR improve its technical assistance and outreach efforts, improve its oversight of the operating divisions and State-administered grant programs, improve its data collection and analysis systems, and provide regular staff training. Currently, OCR conducts preaward reviews only of facilities applying to the medicare programs, and its compliance review activities are limited. HHS/OCR appears to have ignored the Commission's recommendations and continues to operate an ineffective civil rights enforcement program.²¹

Recommendation: HHS should reconvene the Civil Rights Review Team to revisit recommendations made in 1993. The Department should develop a new review team composed of staff from several agency elements, including OCR, to conduct a thorough examination of civil rights enforcement activities in OCR. The team should issue a new report and followup reports on a biannual or triennial basis.

The team should also establish an action plan to carry out the recommendations that have been made by the Commission and other agencies. The team should identify the steps needed to address these recommendations, and OCR should assign staff to carry out such steps. In

¹⁹ See chap. 2, p. 27-29.

²⁰ See chap. 2, pp. 29-31.

²¹ See chap. 2, p. 31.

particular, the team should examine the current distribution of staff among the regions and in headquarters and determine the most appropriate staffing levels for each office in order for OCR to produce policy materials, conduct research on civil rights issues in the health care context, conduct compliance reviews and investigations, and provide technical assistance, outreach, and education.

Further, OCR should develop a monitoring system to improve its compliance activities with respect to Hill-Burton and other facilities. This monitoring system should include formal, uniform procedures to ensure that facilities are in compliance. The system should include mechanisms to monitor compliance agreements and to improve reviews.

Strategic Planning

Finding: The purpose of the strategic plan is to announce priority issues and develop a plan of action for addressing those issues. OCR's existing strategic plan is problematic for three reasons: it has not been updated since 1994 when it was developed; it was developed with little input from outside advocacy groups; and its civil rights provisions have not been effectively integrated into the Department's strategic plan and thus have not been integrated into health care initiatives targeting women and minorities.²²

Recommendation: OCR should issue a new strategic plan as soon as possible. This new plan should include priority issues developed in part through "customer service outreach meetings" organized by the regional OCR operations. The new strategic plan should be based on input from appropriate staff in the operating divisions, as well as health care policy and advocacy groups, civil rights groups, and other important stakeholders such as community and outreach groups. The new strategic plan should be developed in conjunction with the Department's strategic plan to ensure that civil rights is incorporated into all Department operations.

Finding: OCR's strategic plan is supplemented by annual performance plans required by the Government Performance and Results Act (GPRA) and by annual civil rights implementation plans required by the Department of Justice. In many ways, these plans are overlapping

and provide similar information. For example, both the strategic plan and the FY 1999 GPRA annual performance plan focus on specific areas, such as: (1) reducing discrimination in adoption and foster care; (2) reducing discrimination in managed care settings; (3) increasing access to HHS services for limited-English-proficient persons; and (4) increasing compliance with title VI, section 504, and the ADA in Temporary Assistance to Needy Families (TANF) programs.

However, as the Commission found in its 1996 report on title VI, HHS civil rights implementation plans do not serve as OCR management tools, as intended by the Department of Justice. The plans fail to identify specific objectives, and they fail to identify the resources needed to accomplish those objectives, including staffing and budgeting. In addition, the implementation plans are not thorough enough to provide the Department of Justice with the information needed to evaluate OCR's civil rights enforcement program. In short, OCR's implementation plans appear to be only an attempt to fulfill the DOJ requirement and not the effective planning mechanism they were intended to be.²³

Recommendation: OCR must develop a comprehensive civil rights enforcement plan that incorporates the qualities of its implementation plan, strategic plan, and annual work plans. Developing one comprehensive plan which meets all of the requirements specified by the GPRA and DOJ will reduce the amount of staff resources required to develop, implement, and track these plans. The ideal civil rights enforcement plan should embody:

- Specific short-term objectives and long-term goals.
- Specific timeframes or deadlines for their accomplishment.
- Specific strategies for their accomplishment.
- Consideration of both available and projected resources and budget constraints.
- Application of these priorities and plans to each type of funding program administered.
- Application of these priorities and plans to the enforcement mechanisms for block grant and continuing State programs.
- Consideration of the number of expected complaints or other increase in workload.

²² See chap. 2, pp. 31–36.

²³ See chap. 2, pp. 36–40.

In particular, this comprehensive enforcement plan should focus on title VI issues to which OCR has paid little attention, such as clinical research, managed care, and racially motivated medical redlining. This enforcement plan should be updated every 6 to 12 months and should be adjustable to increases and decreases in actual compliance activities and responsibilities and new or developing civil rights enforcement issues, such as agency initiatives and concerns of recipients, participants, beneficiaries, and affected communities.

Finding: HHS' most recent strategic plan, issued in 1997, does not adequately address civil rights issues by failing to fully address gender, racial, and ethnic differences in access to health care services, health care financing, and health research. OCR is mentioned in the context of adoption and foster care, health services for the elderly, community-based and home health care, and medicaid and medicare. However, OCR's enforcement activities and its role in initiatives to eliminate disparities in health status are not clearly defined. In addition, the HHS strategic plan provides little insight as to how the goal of improving access to health care, as well as the other goals, will be accomplished. The plan does not provide results-oriented goals and there is no departmentwide initiative focusing on improving civil rights enforcement. Further, a system for evaluating performance and tracking accomplishments is not identified.²⁴

Recommendation: HHS should ensure that civil rights issues are directly addressed in the strategic plan. Enforcement of civil rights must be integrated into all HHS programs and should be a critical standard for measuring agency performance. Performance over time should be monitored through the collection of data on the progress of HHS in improving civil rights enforcement.

Future budgeting and planning should reflect the importance of civil rights enforcement at HHS. No civil rights enforcement plan should be approved without details on the resources needed to implement all components of the plan and requisite tradeoffs within the total HHS budget. Any proposal for significant increases or decreases in HHS civil rights resources must be supported by an analysis of the impact of that

adjustment on the Department's capacity to carry out its civil rights responsibilities.

The Secretary must require that the director of OCR develop and update periodically an inventory of the functions and activities necessary to have a strong and sustainable civil rights enforcement program. At minimum, the director of OCR must prioritize activities based on an assessment of risks and benefits, financial and otherwise, and should assess the total resources needed to effectively carry out the Department's civil rights responsibilities. The assessment of priorities and resources must anticipate the potential effects of various initiatives. The difference between the resources available and the resources needed should then be further examined to determine which programs can be streamlined or consolidated.

Finding: OCR has failed to address sufficiently the final two action principles in its strategic plan, which focus on selecting employees who share OCR's vision and creating an organization that encourages employee training and development. There have been very few new hires and very little training. Without additional staff and training, OCR cannot accomplish this part of its strategic plan, which is integral to strengthening its civil rights enforcement efforts. The final goal identified by the strategic plan involves redeveloping the infrastructure of OCR. To achieve this goal, OCR planned to train its staff to ensure that they have the skills needed to perform their jobs and develop contact with external civil rights experts. However, this appears to have been a low priority because little progress on this goal has been made. Staff receive minimal training aside from on-the-job training, and formal training plans have not been developed.²⁵

Recommendation: OCR headquarters should take the leadership role in civil rights training not only for its staff, but for all HHS staff. OCR should develop a written training policy whereby OCR staff would be required to provide training on civil rights statutes to its staff on a regular basis. The policy should also have training assessment needs as a component, and an evaluation mechanism to ensure that staff have the updated knowledge and skills to enforce old and new provisions of the civil rights statutes.

²⁴ See chap. 2, p. 34.

²⁵ See chap. 2, pp. 31-33.

In conjunction with the necessary civil rights training, OCR should provide staff with training on investigative procedures for assessing civil rights compliance. A series of training sessions should be held annually and should include several components, such as an overview of civil rights from a legal perspective, civil rights in the health care context, investigative methods, and enforcement procedures.

Finding: OCR has also had mixed success in accomplishing the three long-range goals identified in the strategic plan: (1) provide leadership in the creation and evolution of a departmentwide civil rights program, (2) increase access to and participation in HHS programs through the prevention or elimination of unlawful discriminatory barriers and practices, and (3) redevelop the infrastructure of OCR to help HHS accomplish its civil rights mission. It appears that the most significant progress has been made in working with the operating divisions on various initiatives. OCR, however, has failed to make itself a well-known force in the agency, and, as such, has not provided leadership in the creation and evolution of a departmentwide civil rights program. OCR remains isolated from the rest of the agency and, although it participates in several agencywide initiatives, it appears to play more of a reactive than proactive role in civil rights issues facing the agency.²⁶

Recommendation: OCR should provide the leadership role in the creation, implementation, and evolution of departmentwide civil rights programs, initiatives, and policies. It should be the major force in recommending civil rights legislation in health care, ensuring that there is a civil rights component in all departmental programs and operations, and keeping the Secretary abreast of civil rights issues so that they remain a focus at the Department. OCR should initiate new departmental civil rights initiatives and have a network with regional staff throughout HHS so that it is informed about the relevant issues in health care that affect minorities and women nationwide. OCR staff should have the leadership role on all departmental boards, task forces, and interagency committees related to civil rights. It should be the major departmental liaison with other Federal civil rights offices, maintaining routine correspondence with these

agencies, especially with regard to their initiatives in the health care area.

This can only be accomplished through the support of the Secretary of HHS. The Secretary, in partnership with the director of OCR, must develop a policy statement that clarifies the role of OCR in HHS programs and operations. With this policy statement, the Secretary should require that OCR be involved in all new programs and initiatives to ensure that civil rights issues are appropriately addressed. Further, OCR must serve in an advisory capacity in all aspects of HHS programs, and must be consulted with in the development of policies and procedures that affect access to quality health care.

Finding: OCR does not clearly define its output and outcome measures. OCR relies on data from previously investigated recipients as performance outcome measures required under the GPRA. OCR plans to collect data regarding access to services received before the initiation of a review (or during the review/investigation if preexisting data are unavailable) and after the review. However, there appears to be confusion over the type of data that should be used to evaluate performance. OCR cites the GPRA as its authority for collecting data from recipients that will be used to evaluate OCR's performance. However, the title VI regulations are the appropriate authority for data collection. In fact, the Region IX manager stated that the GPRA does not give agencies the authority to require data from recipients, nor did it intend for agencies to use it as an authority to collect data.²⁷

Recommendation: Data received from recipients should be used as outcome measures to determine if OCR's reviews are successful; however, OCR should cite its enforcement authority as the authority for collecting such data, not the GPRA. Performance should also be measured by the impact OCR activities have on HHS funding recipients. Such measures could include the extent of improvements found through monitoring efforts and changes in the types of technical assistance requested.

Finding: The annual operating plans are unwieldy compendiums of reporting forms that specify investigation, review, and outreach projects. For example, the plans for Region I comprise more than 100 pages of reporting forms.

²⁶ See chap. 2, pp. 32–33.

²⁷ See chap. 2, pp. 35–36.

Although it appears as if great effort is put into creating these reports, little information is provided as to why certain issues or locations are targeted for outreach or investigation, other than a general reference to the director's or Secretary's priorities. In the annual operating plans, OCR does not address crucial issues such as quality of care; the effect of structural changes (such as changes in medicare and HMOs); and racial, ethnic, and gender disparities in medical procedures. Many of the investigation, review, and outreach efforts identified in the FY 1998 Annual Operating Plan focus on limited English proficiency, the Americans with Disabilities Act, and section 504 of the Rehabilitation Act. In addition, while many of the projects look at whether there are disproportional services to minorities based on statistical analyses, it is not clear whether OCR performs an in-depth analysis of the quality of care given to minorities (including the quality of medical procedures, the physical environment, and the care of health providers) to determine if it is equivalent to the care given to nonminorities. Such standard statements, with little description, fail to provide sufficient detail as to how the regional staff will conduct these reviews. In fact, there is little description of expectations, methods, and planned outcomes of the projects in most of the annual operating plans.²⁸

Further, activities identified in the regional operating plans seem to be redundant, and there is no mention of coordination among regions that can result in duplication of efforts. In the annual operating plans, it is unclear how the objectives of an activity, such as a compliance review, will be accomplished, nor is it clear how discrimination will be eliminated. In addition, the regional plans do not clearly show the effects of planned activities on staff and resources, such as staff hours and travel costs. Because they are not specific with regard to objectives and strategies, the operating plans do not serve as effective planning tools for civil rights enforcement, program development, or budget allocation.²⁹

Finally, the regional offices do not appear to use consistent planning methods. For example, Region X identified several facilities in which it will do compliance reviews, yet the issues being

evaluated were "not determined yet." Region V, on the other hand, identified issues to be reviewed, yet had not determined which facilities would be reviewed. These discrepancies among planning techniques and projects conducted could result in uneven implementation of civil rights statutes, policies, and regulations throughout the country. The regional plans and subsequent significant activity reports reviewed by the Commission differed in content and volume. Some were lengthy reports that included descriptions of "special" activities that were really routine, day-to-day responsibilities, while others provided very limited detail and appeared to be incomplete.³⁰

Recommendation: OCR should provide examples of the region's best strategies and provide overall direction for regional office activities. OCR should also streamline its annual planning process. Regional plans should be based on a comprehensive civil rights enforcement plan developed by OCR headquarters staff. Regional offices should plan full-scale compliance reviews of HHS funding recipients on a rotating basis, so that *all* recipients are reviewed over a specified period, such as once every 3 years. Full-scale compliance reviews should be standardized to incorporate all of the civil rights statutes under OCR's authority. Thus, the planning process would merely identify the recipients to receive compliance reviews and would identify other responsibilities of OCR regional staff, including preaward reviews, investigations, and technical assistance, outreach, and education.

Further, variation in what regions report will be minimized if OCR provides assistance to regional offices in developing, implementing, and reviewing their plans. There should be uniform understanding of activities that are required, day-to-day or routine tasks, and activities that are based on special circumstances or that are specific to a particular region.

Budget

Finding: OCR operates under severe budgetary constraints. OCR's responsibilities and workload have increased over the past several years, while its funding and staffing levels have decreased. OCR's budget has not kept up with inflation. Compared with the rest of the De-

²⁸ See chap. 2, pp. 36-37.

²⁹ See chap. 2, pp. 37-39.

³⁰ See chap. 2, pp. 37-38.

partment, OCR's budget is infinitesimal, accounting for only 0.0054 percent of the entire HHS budget. This suggests an overall low priority for civil rights at HHS.³¹

Recommendation: OCR's severely limited budget requires persistent and forceful attempts to achieving funding increases from the Secretary and Congress. The petition for additional funding must be accompanied by analysis of where additional resources are needed and how OCR operations will benefit from increased funding. In addition, OCR must persuade HHS to redistribute current departmental funds so that a larger percentage of the budget is allocated for civil rights enforcement efforts.

Finding: Budget limitations have hampered OCR's ability to accomplishing many activities effectively. Almost all of the regional offices stated that lack of resources has placed them at a disadvantage, making it difficult for them to accomplish their mission.³²

Recommendation: Until OCR receives the resources and staff needed to carry out its mission, responsibilities should be reevaluated and resources redistributed where they are most effective and have overreaching impact on other operations. Under regular guidance and oversight from headquarters, regional staff should concentrate on conducting procedures at field locations, such as onsite compliance reviews, onsite complaint investigations, local community outreach and public education, and onsite assistance to recipients in the relevant locality. Operating division staff should be delegated other daily implementation and enforcement activities, including compliance reviews and investigations that do not have to be conducted locally, such as preaward and postaward desk audit reviews, data collection and analysis, and reviewing and evaluating recipient self-assessments and assurances of nondiscrimination. Headquarters staff should be responsible for providing policy and legal guidance and monitoring and overseeing the daily implementation and enforcement activities of regional and operational level civil rights staff.

To accomplish this, a separate civil rights unit within each operating division should be created. A minimum of 25 persons and a civil

rights manager should comprise the staff of the civil rights unit. These units would be responsible for conducting preaward reviews, collecting and analyzing data, and reviewing recipients' compliance with civil rights statutes. All staff in these units must have civil rights compliance and enforcement experience essentially equivalent to OCR staff. However, there must be strict oversight and monitoring by OCR. All final decisions concerning compliance must be made by OCR. Thus, any letter of finding or preaward correspondence must be approved and executed by the director of OCR. Alternatively, the operating divisions should fund full-time employees to be located in OCR to conduct these activities.

Finding: OCR does not have a separate budget for title VI enforcement or for the other civil rights authorities it enforces. Thus, OCR is unable to track its enforcement efforts by statute and authority to ensure that all civil rights statutes and regulations are properly monitored and enforced. As such, it is unable to determine, for example, the extent to which resources for title VI enforcement responsibilities vary relative to those allocated for overall external civil rights enforcement.³³

Recommendation: HHS should establish a system for monitoring and tracking expenditures on each type of civil rights enforcement activity, including complaint investigations, preaward reviews, postaward reviews, staff training, technical assistance, outreach, and education. The system should delineate expenditures on these activities that are specifically associated with title VI and title IX implementation and enforcement. By tracking the amount of time and resources devoted to each civil rights law, OCR can have a means of justifying budget and staffing requests that will strengthen its title VI and title IX implementation and enforcement program. This system also will enable OCR to ascertain increases or decreases in title VI and title IX resources and base essential enforcement decisions, such as staffing assignments and assignment priorities, upon such information.

Finding: The FY 1999 budget supports a compliance program that focuses on implementing the adoption and foster care nondiscrimination provisions of the Small Business Job Protection Act of 1996, ensuring nondiscrimina-

³¹ See chap. 2, pp. 41-44.

³² See chap. 2, pp. 41-42.

³³ See chap. 2, p. 42.

tion in the Temporary Assistance to Needy Families (TANF) program, and supporting quality health care access for racial and national origin minorities and persons with disabilities to managed care plan services, children's health programs, HIV/AIDS services, and home health care services. However, the budget fails to include a formalized system for developing policy guidances, comprehensive full-scope civil rights activities, and training for the staff.³⁴

Recommendation: The budget must be closely tied to annual planning. In future budget requests, OCR must plan for full-scale compliance reviews of *all* recipients and preaward audits of *all* applicants. Further, budget requests must identify the reasons for hiring additional staff, such as the need for producing current, up-to-date policies and enhancing civil rights enforcement activities, such as pre- and postaward reviews. The budget should include additional funding for technical assistance, outreach, and education for recipients, beneficiaries, advocacy groups, and other important communities, as well as increased funds for training of OCR staff.

Finding: The FY 2000 HHS budget allocated \$5 billion to "health education, prevention and treatment services specifically targeted to minority Americans" which includes \$145 million for the departmental racial health disparities initiative. None of the \$5 billion appears to be for civil rights enforcement, which should be the first step in eliminating disparities in health care by race and ethnicity. HHS ignores the need for improved civil rights monitoring and enforcement, almost placing the onus for improved health care entirely on the minorities who face discrimination in access to health care.³⁵

Recommendation: In addition to increasing funding for OCR, the HHS budget must include funds for civil rights enforcement activities. For HHS to achieve its goal of eliminating health care disparities, HHS programs must incorporate civil rights enforcement issues into their operations. This can be accomplished through additional funding for OCR, the operating divisions, and programs of HHS. Funding for OCR should be increased to at least \$40 million so that additional staff may be hired, training can

be provided to staff, and all-inclusive civil rights enforcement activities can be undertaken.

Further, funding must be provided for increased outreach, education, and technical assistance activities related to civil rights for all HHS programs. HHS, under the guidance of OCR, must prepare and distribute information and policy guidances to funding recipients, program beneficiaries, and the general public concerning the application of civil rights laws to health-related programs and issues. The most effective way to combat disparities in health care is to increase public awareness of civil rights in the health care context, and to have sufficient resources and staff to uncover violations of civil rights statutes and regulations.

Finding: While the Clinton administration has proposed a 15 percent budget increase for civil rights enforcement, it is targeted to only six agencies and does not include HHS. Further, there is no mention of civil rights in the Federal budget for FY 2000. Although efforts to reduce racial disparities in health status are identified in the budget, the FY 2000 budget fails to take into account that, absent effective civil rights enforcement, racial disparities in health care will never be eliminated.³⁶

Recommendation: The President and Congress need to recognize the importance of civil rights enforcement activities in relation to the elimination of disparities in health status. Increased funding for education, prevention, and treatment services must be accompanied by increased funding for identifying potential violations of civil rights statutes in the health care context and increasing public awareness of the application of civil rights laws to health care issues.

Staff Training

Finding: As the Commission found in its 1996 report on title VI enforcement, OCR's staff training is limited, consisting only of on-the-job training for new staff and annual training seminars on new civil rights developments. OCR staff identified several areas where more training is needed, particularly: title VI health care issues, case law, managed care issues, investigative techniques, and the difference between disparate impact and disparate treatment. Staff also stated

³⁴ See chap. 2, p. 42.

³⁵ See chap. 2, pp. 42-43.

³⁶ See chap. 2, p. 44.

that refresher training was needed to address new ideas and new ways of handling cases.³⁷

Recommendation: OCR should regularly provide training to its staff and recipients' staff on issues of title VI enforcement and compliance, including, but not limited to, the following areas: enforcement procedures, such as compliance reviews and complaint investigations; the nexus between title VI enforcement and a particular program's objectives and administration; the nexus between other civil rights enforcement provisions and ensuring nondiscrimination in federally funded activities; title VI nondiscrimination requirements in HHS programs; and updates on HHS' policy, case law, statutes, and regulations affecting title VI enforcement and compliance.

All OCR professional staff, particularly those staff members in key leadership positions, should have training in civil rights enforcement. They should have practical experience in actually conducting administrative enforcement activities such as compliance, preaward, and desk audit reviews; complaints processing and investigation; and technical assistance activities. Without such experience, candidates for positions in OCR should not be ranked among the most highly qualified for the position.

Finding: OCR does not have a comprehensive training plan for its staff; training needs are assessed on an as-needed basis. Using a team concept, equal opportunity specialists are trained by other staff who have more experience and who are more skilled than newer employees. For example, equal opportunity specialists (EOS) stated that branch chiefs conduct on-the-job training in Region I. Many of the OCR employees the Commission interviewed stated that training was not sufficient throughout the regions. For example, in Region VII, most of the investigators have not had formal investigator training. In many cases, regional attorneys provide training on investigative techniques and other issues, but it is not done in a consistent manner.³⁸

The lack of training resources has resulted in regional staff taking innovative approaches to acquiring training. For example, some regions partner with other Federal agencies and attend

training sponsored by the operating divisions and staff divisions. Other regional offices are able to negotiate free or reduced cost training. One regional manager stated his office has worked with other civil rights agencies to receive training or they have "begged or borrowed to obtain funds" for training.³⁹

Recommendation: An ad hoc approach to training ultimately will have a negative impact on the effectiveness of a civil rights enforcement agency. Staff must be trained in up-to-date investigative and negotiation techniques, must have "refresher" training on the laws they enforce, and must have training on the latest technology. Further, new staff must have formal training in addition to on-the-job training if they are to be effective and fully understand their responsibilities.

HHS and OCR must ensure that adequate training funds are available so that OCR staff can receive appropriate training on an annual basis. Training should not be an "afterthought" that is provided only if funds are available. OCR must develop an annual training plan to be included in annual budget requests.

Finding: OCR conducted a major training initiative in 1993. The initiative consisted of several civil rights forums, conducted for about a year on a quarterly basis. The forums served the Department's operating and staff divisions as well as title VI, Hill-Burton, and title IX funding recipients. However, in the 6 years that have elapsed since then, OCR has not provided similar departmentwide civil rights training.⁴⁰

Recommendation: OCR must have the resources so that it can provide training and technical assistance to other HHS components, particularly in the regions. It should initiate training and technical assistance on a routine basis for OCR staff, operating division staff, and recipients. Funds should be allocated so that OCR can reinstitute the civil rights forums. The forums should be accompanied by training and guidance documents that are permanently available to Department staff, the public, and other groups and organizations, such as private health care facilities and other stakeholders.

³⁷ See chap. 2, pp. 44-47, 50-51.

³⁸ See chap. 2, pp. 44-47.

³⁹ See chap. 2, pp. 44-47.

⁴⁰ See chap. 2, p. 46.

Computer Technology

Finding: OCR does not make full use of computer technology. For example, weekly reports sent to regions are primarily in hard copy form, not through electronic mail. Further, although OCR has used the Internet to distribute information on its civil rights enforcement responsibilities, the information on OCR Web site to date is far from complete. For example, there is no discussion of title IX; nor is there a way electronically to file a complaint. In addition, 3 of the 10 regional offices provide OCR information on their Web sites, but the information included differs by region.

As stated above, OCR does not have a formal system for tracking expenditures on the various civil rights enforcement activities (complaint investigations, preaward reviews, postaward reviews, staff training, and technical assistance). OCR relies on its Case Activity Tracking System, but the system does not track expenditures by specific program.⁴¹

Recommendation: OCR should receive increased funding to improve its computer technology resources. Staff must be trained on the use of computers, including the use of e-mail and the Internet, so that information can be made available to OCR staff and the public. Increased use of computer technology can improve communication between headquarters and the regions, and among the regions.

OCR should use other databases and sources for disseminating civil rights information. It should expand its resources for information to include outside agencies. It also should network with universities, particularly medical schools, libraries, health care providers, hospitals, community organizations, and medical associations that use technology to disseminate their information nationwide. In addition, by using the Internet, OCR can make civil rights information widely available. OCR should establish a comprehensive electronic library, available on the Internet, containing all of OCR's key documents. In addition, OCR should make it possible for people to file complaints through the Internet. OCR's current Web site also should be upgraded to include more information on title VI and title IX. Contact names and links to regional OCR Web sites should be provided.

OCR must also make use of computer systems for tracking civil rights enforcement activities and expenditures on those activities. This information is crucial for planning and management purposes. OCR staff should track this information to determine if sufficient time is spent on certain activities, such as title VI enforcement, as well as to justify budget requests for such activities.

Chapter 3. Implementing Civil Rights Provisions: OCR's Rulemaking and Policy Development

Summary

A critical element of any agency's civil rights enforcement program is the development and dissemination of regulatory policy, which can take the form of regulations, guidelines, directives, and policy guidance documents. Such policy informs program beneficiaries, funding recipients, and regional OCR staff of the rights and responsibilities conferred by the relevant civil rights provisions. In the health care context, OCR is charged with developing and disseminating regulatory policy under title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, titles VI and XVI of the Hill-Burton Act, and the nondiscrimination provisions of the block grants funded by HHS. Importantly, OCR largely has failed to develop policy guidance on specific issues relating to discrimination under these statutes. For example, with respect to title VI, OCR has failed to produce comprehensive policy guidance in a number of contexts in which discrimination on the basis of race, color, or national origin may take place. These include nursing homes, medical school admissions, employment, managed care, organ transplantation, and numerous others. For title IX, OCR has not developed guidance for discrimination on the basis of gender occurring in medical study and practice, and in participation in medical research.

The extent of OCR's inaction on health care regulatory policy development is cause for concern. For instance, OCR has failed to update its titles VI and IX regulations to reflect important developments in civil rights law, such as the expansion of jurisdiction created by the Civil Rights Restoration Act of 1987, and the changes in affirmative action brought about by the Supreme Court's decision in *Adarand Constructors*

⁴¹ See chap. 2, pp. 48–49.

v. Pena.⁴² Although the Department of Justice Coordination and Review Section (DOJ/CORS) directs agencies not to update either set of regulations, OCR at least should have adjusted the appendices of these regulations to list the programs funded by HHS, rather than those actually funded by the Department of Education (DOEd). Moreover, OCR has never promulgated any regulations implementing the nondiscrimination provisions of block grant programs.

OCR's lethargic approach to regulatory policy development is reflected even more prominently by its efforts to develop policy guidance. For example, although DOJ/CORS regulations require OCR to augment its regulations with published guidelines on specific programs, OCR has never complied. Moreover, OCR has developed very few policy guidance documents, none of which have ever been published in the *Federal Register*. The few examples of recent policy guidances address limited English proficiency (LEP), multi-ethnic adoptions, and, in draft version, welfare reform. Only one of these, LEP, applies specifically to health care programs. Overall, OCR's policy development record has been unusually dismal. It has been characterized largely by inactivity and a failure to provide guidance necessary to ensure that HHS funding recipients and OCR's own investigative staff can ensure full compliance with civil rights provisions.

Nondiscrimination laws for federally funded programs are complex, particularly with regard to health care. Definitions and standards applicable to health care must be developed and clarified for OCR to properly evaluate compliance. For example, OCR has not yet established definitions for equal access, quality of care, and appropriateness of care so that an investigator may determine whether minority and female patients receive the same medical diagnosis, testing or treatment as white males. In addition, the application of evidentiary standards in health care discrimination cases must be clarified. In impact cases, for example, there is no clear determination of what is required for plaintiffs to establish the element of harm, and what would constitute a "legitimate justification" for a health facility's discriminatory policies. Further, these standards should be promulgated with regard to specific

types of health care cases, rather than in general. With the exception of a brief 1981 internal policy memorandum describing the test used to evaluate whether a recipient's justification is legitimate, OCR has declined to clarify any of the above definitions or standards as they relate to health care.

In addition to definitions and standards, nondiscrimination requirements relating to specific programs, facilities, and institutions are also required elements of civil rights policy development. Here again, OCR has been reluctant to take the initiative. For example, changes in the health care industry have brought about new forms of discrimination. Managed care organizations may be discriminating against minorities through selective marketing and redlining techniques, however, OCR has not disseminated any policy guidance in this important area. Further, changes in the law have spawned gray areas in which the responsibilities of recipients have become unclear. For instance, medical schools and other educational institutions require clarification of their nondiscrimination responsibilities in the aftermath of the *Adarand* case, which substantially limited the use of affirmative action in admissions to such programs. OCR has been unresponsive to this issue as well. Other contexts requiring further guidance from OCR are limited English proficiency, nursing home segregation, discrimination against physicians who serve minorities, failure to include minority and female participants in clinical research programs, and unequal access of minorities to donated organs.

HHS officials have cited multiple reasons for the failure of OCR to develop regulations and policies. Some have cited the relatively small number of title VI and IX complaints in the health care area as a reason for focusing on other contexts, such as disability-based discrimination. However, the lack of complaint activity should not indicate to OCR that race and gender discrimination in health care is of little concern. To some extent, the dearth of complaints may be due to the undeveloped state of the law in health care, for which OCR is partially to blame: if OCR had developed specifically focused nondiscrimination policies sooner, perhaps program participants and beneficiaries would have been aware earlier of their right to equal access to health care in federally funded

⁴² *Adarand Constructors, Inc. v. Pena*, 515 U.S. 200 (1995). See chap. 3, pp. 116-17.

facilities, and perhaps would have filed more complaints.

Another justification that has been cited is the “ad hoc” approach to policy development adopted by OCR. Under this ad hoc approach, OCR policy staff generally wait until an issue presents itself in the context of an actual case or cases, before deciding how the issue should be resolved. Staff have indicated they do not wish to “make a policy in a vacuum,” because “it may not do what it was intended to do.”⁴³ According to staff, OCR will consider developing policy in cases where there has been a significant divergence of opinion or confusion among the regions regarding the proper resolution for a particular issue or set of issues. Headquarters staff assert that when such disagreement or confusion arises, OCR may develop guidance to explain or clarify its position. Nonetheless, the Commission has identified several areas that appear to be mired by confusion, including discrimination by managed care organizations and evidentiary burdens for disparate impact cases, but because there have been few complaints filed, OCR has promulgated little policy. This ad hoc approach to policy development may have generated a vicious cycle in which OCR’s failure to disseminate nondiscrimination policies in certain issue areas has kept participants and beneficiaries in the dark about their health care rights, preventing them from filing complaints, and in turn reinforcing OCR’s perception that discrimination in those areas is not a serious problem.

A General Assessment: Inattention to Health Care Issues in Policy Development

Finding: In 1993 HHS’ Civil Rights Review Team found that one of the most crippling factors preventing OCR from mounting an effective civil rights program has been the absence of clear definitions, or standards, establishing what constitutes discrimination in the health care system. Further, it noted that to the extent HHS has developed policy, it has not been effectively communicated to civil rights staff. As a result of HHS’ failure to develop and communicate its policies on title VI, external civil rights (title VI) enforcement staff and funding recipients are unfamiliar with HHS’ compliance expectations. HHS/OCR largely has failed in its efforts to de-

velop standards for assessing discriminatory practices not just under title VI, but title IX, the community assurance provision of the Hill-Burton regulations, and the nondiscrimination provisions in block grant statutes as well. In general, the Commission finds in this report that most of the Commission’s recommendations for regulatory and policy development given in its 1996 title VI report have been largely ignored.

OCR’s general failure to use regulations and policies to implement civil rights laws has had a devastating effect on the agency’s ability to conduct the thorough, comprehensive enforcement needed to ensure equal access to quality health care in a complex and ever-changing health care environment. As such, discrimination in health care has been allowed to persist.⁴⁴

Recommendation: The Commission recommended in its 1996 title VI report that OCR should develop policies concerning title VI implementation and enforcement, such as: (1) procedural issues particular to State-administered programs, such as HHS’ block grant programs; (2) discriminatory situations particular to HHS’ programs, such as equal opportunity for racial and ethnic minorities to participate on health and peer review boards; and (3) discriminatory practices prohibited in specific types of HHS programs, such as discriminatory criteria for awarding research grants. In addition, OCR should develop policy guidance on the following:

- Medical redlining (failing to provide health care services or financing based on race, as reflected by geographic area of residence).
- Adverse effects of hospital closure and relocations on minority communities.
- National origin related issues (including treatment of patients with limited English proficiency).
- Access to a regular care provider.
- Continuity of care.
- Reliance on hospital outpatient departments and emergency rooms.
- Length of time in waiting for care.
- Unequal participation of minorities and women in medical research programs at university/teaching hospitals.
- Unequal access to health care financing programs.

⁴³ See chap. 3, p. 67.

⁴⁴ See chap. 3, pp. 67–68.

- The practice of restricting admissions to patients who are referred by physicians with staff privileges, if area residents who are low-income minorities are unable to gain admission as a result.
- The practice of restricting admissions to patients who are referred by physicians with staff privileges, if few or none of such physicians will treat medicaid patients and the result is to exclude medicaid patients from the facility or from any service of the facility.
- The practice of requiring an advance deposit before admitting or serving patients, if the effect is to deny admission to some persons or cause them delay in obtaining services.
- Inadequate minority participation in hospital construction programs.

Further, OCR should assign staff permanently to developing policy statements on new or novel legal issues affecting civil rights compliance, such as appellate reviews of case decisions, amendments to statutes, and revisions in regulations or policies affecting title VI compliance. Policy development staff should examine existing policies to determine the extent to which they should be updated. This staff also should develop a mechanism for ensuring that all staff, beneficiaries, organizations, and agencies that need policy guidance receive such guidance on a regular basis.

Lack of Definitions and Standards to Ensure Compliance: Defining “Equal Access”

Finding: Equal access is a concept fundamental to Congress’ purpose for enacting civil rights laws such as title VI and title IX. It is difficult to evaluate inequities in access to health care without clear definitions and standards for what constitutes equal access to quality health care services. Standards for the provision of health care services must address the inequities in both access to and quality of care that continue to exist on the basis of race, ethnicity, and gender. Without clearly defining equal access, OCR will continue to face difficulty identifying violations and enforcing civil rights in the health care context.

A definition for “equal access to quality health care” could provide a standard that recipients of HHS funds would be required to meet to ensure that civil rights protections are being

accorded to all “customers.” Currently, there is no single, adequate definition of equal access to quality health care. It should be noted in this context that Congress enacted an Equal Educational Opportunities Act (EEOA) and Equal Credit Opportunity Act (ECOA) to provide further civil rights protections on the basis of race, color, national origin, and sex. EEOA requires “equal participation” in public education programs. However, there is no equivalent civil rights statute that protects equality of opportunity in health care.⁴⁵

Recommendation: OCR should define clearly the concept of equal access to quality health care, and provide guidance to its staff in investigating charges of the denial of equal access to quality health care. Specifically, OCR should develop a policy statement defining “equal access” in the health care context. In developing this policy statement, OCR first should review the work of the many commentators who have written on equal access to health care as a civil right. The statement should contain an opening section illustrating the inequities in gaining access to health care that have confronted Americans who are members of racial and ethnic minority groups or women, both historically and in the present. It also should contain a section on how Congress has sought to remove these inequities by enacting statutes such as title VI and title IX, and the nondiscrimination provisions in block grant statutes. In addition, it should contain a discussion on the authority Congress has given OCR to promulgate regulations under title VI, Hill-Burton, and title IX. OCR should refer to the provisions in these regulations that define discrimination.

This policy statement should identify the principal forms of discrimination on the basis of race, color, national origin, and sex in the health care industry. It should observe how selecting patients on the basis of method of payment creates discrimination as defined in the regulations. The statement should discuss the myriad of other policies and practices health care providers engage in that create discrimination on the basis of race, color, national origin, and sex and explain *why* specific practices result in discrimination. For example, it should explain that such factors as distance, travel time, and other trans-

⁴⁵ See chap. 3, pp. 68–75.

portation difficulties, excessive waiting times in emergency rooms, and inadequate means of addressing language barriers all may constitute discrimination and denial of equal access to quality health care. It should identify the need for service as the only legitimate determinant of who receives health care and the manner in which it is delivered. It should state explicitly that all other determinants, particularly method of payment, cannot play a role without potentially implicating title VI regulatory provisions and presenting possible civil rights violations under the statute or its regulations.

Further, OCR should provide a specific definition for the term "equal access." In developing a definition of equal access to quality health care, OCR should consider that the term "access" is "a broad and often vaguely defined concept" that has encompassed a number of variables including the supply and availability of health care providers, health insurance coverage, and identification and removal of barriers to access. To better focus this definition and to assist recipients in understanding fully OCR compliance requirements, the policy guidance should establish criteria to evaluate whether "equal access" has been afforded. OCR should explain in its policy guidance that, to provide equal access to quality health care, a health care service provider must first remove all discriminatory policies and practices that result in denial of equal access to quality health care. Further, OCR should explain that it seeks to imbue the term "equal access" with a precisely defined practical meaning that can help the agency to more clearly establish at least the broad parameters of the requirements a health care provider must meet to show compliance.

Therefore, any definition of equal access should contain the following criteria: (1) access to the same quality of health care regardless of race, ethnicity, sex, or method of payment; (2) inclusive, effective research; and (3) assurance that everyone has the availability of appropriate financing. The focus of these criteria must be on consistency in the means of determining eligibility for a service, the medical standards applied for conducting specific procedures, and the quality with which services are provided. In addition, this policy statement must provide a means for OCR to actually observe whether recipients are providing their services in accord

with its policy recommendations. To be as effective as possible, this policy statement should include specific examples of how to provide equal access in different "real-world" contexts.

Defining "Quality of Care"

Finding: For health care to be truly equal, not only must there be equal access to services, but the same quality of care must be available to all individuals. According to one advocacy group, improving the quality of health care will ultimately lower the costs of and increase access to health care. Indeed, every American should be guaranteed access to quality health care. However, it is difficult to ensure such access without a clear understanding of what quality health care is. OCR staff agree that it is difficult to assess the issue of quality of health care. Thus, a standard "civil rights enforcement" definition of quality health care is needed that can be applied during compliance reviews and investigations.⁴⁶

Recommendation: OCR should make it a priority, set forth in policy guidance, that all of its investigations will seek to ensure that all individuals are provided with the same quality health care. To do this, OCR must have a precise definition of what it means when it uses the terms "equal access" and "quality of care." OCR must focus on the quality of care provided when analyzing whether an individual has equal access to care. OCR's definition should incorporate all factors that contribute to equal access to quality health care, such as cultural competency and appropriate care. Further, in defining quality health care, OCR must include standards and criteria for acceptable practices, as well as a recognition of the need for documentation of health care decisions and the physician's responsibility for clinical decisions. Beyond developing a definition of "quality of care," OCR should ensure that, in practice, its assessment of quality of care includes an analysis of medical outcomes (including the health status of the patient), the actual services performed for the patient, and the degree of expertise with which the patient was treated (including the training of the medical personnel).

⁴⁶ See chap. 3, pp. 72-73.

Defining “Appropriate Care”

Finding: The types and appropriateness of treatment one receives are both elements of quality of care. In order to assess whether an individual received equal access to quality care, it is necessary to determine if appropriate care was provided to that patient. However, when asked if they had a working definition of the term “appropriate care” several OCR staff said that they make no determination of what appropriate care is, and that such an assessment may not even be in their jurisdiction, unless discrimination (under a statute enforced by HHS) by a health care provider or facility was alleged by the complainant. Nonetheless, appropriate care, as well as quality of care and equal access, are concepts that are crucial to determining the existence of discrimination. Discrimination occurs not only in the denial of services, but also in the provision of inferior, inadequate, or inappropriate health care services or medical practices.⁴⁷

Recommendation: OCR must ensure that its investigative staff and HHS funding recipients have an understanding of and can apply the concept of “appropriate care” in assessing civil rights compliance. Further, OCR should ensure that its staff and HHS funding recipients understand the standards applied in the medical profession with regards to appropriate care. To accomplish these goals, OCR, with the guidance of medical experts on appropriate medical procedures and practices, as well as civil rights experts (internal and external), should prepare a policy document that discusses appropriate health care delivery or treatment within the context of civil rights enforcement. In developing this guidance, the OCR document should identify the medical standards applied to different health conditions, such as the standard for the appropriate treatment of diabetes or breast cancer. Such guidance should ensure that OCR staff do not improperly dismiss valid complaints because they appear to involve disputes over the types or quality of services received, rather than actual discrimination. OCR has both the authority and the responsibility to evaluate the appropriateness of medical care to determine whether a patient’s civil rights were violated.

Inadequate Remedial Measures: OCR’s “Substantive” Compliance Manual

Finding: OCR has taken steps to reduce the potential for incorrect findings in its compliance reviews and investigations. For example, OCR is in the process of developing a “substantive” compliance manual. This manual will be used by investigative and other key OCR staff to assist in enforcement of the civil rights statutes for which OCR is responsible. OCR’s deputy director has stated that the bulk of OCR’s work on the manual has focused on section 504, the ADA, and the Hill-Burton Act. He stated that the manual eventually would include a chapter on title VI, but that title VI currently is not the immediate focus of the manual. He further stated that it would be more difficult and would take more time to develop a thorough policy analysis and discussion on title VI since it remains an “abstract” area, with little case law to use as guidance. However, considering that there is so little guidance on title VI, and that it is a very important aspect of OCR’s civil rights enforcement responsibilities, it would seem appropriate to focus more attention, sooner rather than later, on addressing title VI-related issues in the manual.⁴⁸

Recommendation: OCR should make title VI-related policy issues a high priority in developing its “substantive” compliance manual. OCR should begin focusing on title VI in this guidance document immediately. In particular, OCR should use the compliance manual chapters on title VI as a basis for individual policy statements. OCR’s section on title VI in its compliance manual and individual policy guidances must address any gaps in DOJ/CORS’ regulatory and policy development. Both should contain discussions on the following: changes in the law created by the Civil Rights Restoration Act of 1987; block grant programs and the development of methods of administration (MOA); and the evolution of title VI in the health care context in judicial interpretations and its implications for OCR compliance standards, particularly with respect to disparate impact discrimination, which appears to be one of the major barriers to equal access to quality health care for minorities and women. OCR also must address pressing issues relating to title VI compliance. These in-

⁴⁷ See chap. 3, pp. 73–75.

⁴⁸ See chap. 3, pp. 75–76.

clude: racial/ethnic discrimination in the managed care industry, particularly discrimination based on impact rather than intent; nursing home segregation; medical redlining; staff privileges and other employment issues for minority doctors; and the extremely small number of minority medical students and practitioners. In addition, OCR's substantive compliance manual should include comprehensive discussions on its role in enforcing title IX and the nondiscrimination provisions in block grants.

Deficiencies in the Title VI Regulations

Finding: The Department of Justice's title VI regulations direct Federal agencies to develop their own regulations to implement title VI. Although DOJ also has directed Federal title VI enforcement agencies not to revise these regulations, it is the Commission's position that some changes in the regulations are required for HHS to more effectively enforce the law. In its 1996 report on title VI enforcement, the Commission found that HHS has not updated its title VI regulations since 1980. As a result they do not reflect important substantive changes made in the law since then. For example, they do not reflect the clarification Congress made to title VI by the Civil Rights Restoration Act of 1987. Under this act, Congress overturned the Supreme Court's ruling in the 1984 case of *Grove City v. Bell*.⁴⁹ The act amended the definition of "programs or activities" to restore broad coverage for title VI's nondiscrimination provision rejected by the Court in *Grove City*. In addition, the legislative history indicates that the act left intact the fund termination remedy available when discrimination is "pinpointed" to the program or activity receiving Federal financial assistance, or when the federally assisted program is "infected" by discrimination elsewhere in the operations of the recipient. In addition, the regulations have not been updated to address specifically HHS' block grant programs. Although, in 1986, HHS proposed a rule on nondiscrimination requirements applicable to block grants, that rule has never been issued in final form. Moreover, OCR has not adjusted the regulations to exclude references to educational

programs that were operated by the Department of Health, Education, and Welfare.⁵⁰

Recommendation: OCR should update its title VI regulations to reflect changes made in the law with the Civil Rights Restoration Act and to address block grant programs. HHS should also revise its title VI regulations to remove references from the Department of Education regulations. As the Commission recommended in its title VI report, HHS must issue guidance and clarification specific to the current and practical implementation and enforcement of title VI. First, it must provide its external civil rights staff and funding recipients' staff with regulatory guidance specific to title VI enforcement in *each type* of financial assistance program HHS administers. Second, it must address the clarification made to title VI by the Civil Rights Restoration Act of 1987; title VI implementation and enforcement issues particular to HHS' block grant and other State-administered programs; and the extent of funding recipients' authority to implement affirmative measures to prevent discrimination in their programs and activities.

Deficiencies in Title VI Policy Development

Finding: In addition to developing regulations, the Department of Justice also requires Federal agencies to establish guidelines to implement title VI. The guidelines are meant to serve as a program-specific supplement to the title VI regulations, for each title VI-covered program. The DOJ regulations also indicate that the guidelines should be distributed to recipients, beneficiaries, compliance officers, and the general public. In its 1996 report on title VI enforcement, the Commission found that since its creation as a separate entity from the Department of Education, HHS has not formally published any title VI guidelines for its federally assisted programs, as required by the Department of Justice. Consequently, HHS staff, recipients, and participants in HHS programs may lack critical information concerning title VI compliance requirements. Moreover, HHS' title VI staff and funding recipients lack detailed information on how to conduct title VI implementation, compliance, and enforcement procedures

⁴⁹ 465 U.S. 555 (1984).

⁵⁰ See chap. 3, pp. 77-78.

relative to each of the specific grant programs HHS administers.

Further, OCR staff have said that OCR should issue more policy guidance. Equal opportunity specialists in Region VII noted concern about the lack of formal policy guidance and said the guidance that they do have is often obsolete. The attorney in that region stated that OCR needs to be more aggressive in developing policy guidance and should publish its policies and guidance in the *Federal Register*. The regional manager further noted that little training is provided on OCR's policy documents and guidance, and that the guidance is primarily only for OCR staff internally. The guidance is only written in English and, therefore, cannot be distributed outside the English-speaking community like the OCR fact sheets (which are written in several languages).⁵¹

Recommendation: HHS must promulgate a set of guidelines for title VI implementation, compliance, and enforcement in each type of federally assisted program it administers. As required by the Department of Justice, each set of guidelines should: (1) explain the exact nature of HHS' title VI requirements; (2) specify methods for title VI enforcement; (3) provide examples of practices prohibited by title VI in the context of each type of funding program HHS administers; (4) set forth required or recommended remedial action; and (5) describe "the nature of requirements relating to covered employment, data collection, complaints, and public information." In order for such guidelines to be effective, they should establish methods of administration or requirements for States assuming title VI compliance responsibility for HHS' funding recipients, and ensure that recipients conduct self-assessments of their compliance status and remedy any deficiencies discovered. Such guidelines should include implementation, compliance, and enforcement standards for States with title VI responsibility, including, for example, detailed investigative methods and remedial action procedures. The guidelines must also explain the process for data collection from funding recipients and clarify the type of data and information that must be maintained by recipients and applicants. They also should address requirements

for public education and community outreach related to the nondiscrimination mandate of title VI.

Finding: Since the early 1980s, HHS has issued very few policy directives on title VI enforcement. Further, to the extent HHS has developed policy, it has not been effectively communicated to civil rights staff. The result has been that external civil rights (title VI) enforcement staff and funding recipients are unfamiliar with HHS' compliance expectations. HHS has, however, taken steps to address its deficiencies in the area of policy development. It has assigned a regional civil rights attorney to each of its 10 offices, and according to its strategic plan, HHS intends to develop standards for assessing discriminatory practices, among other goals.⁵²

Recommendation: HHS must commence regularly developing policies on title VI implementation and enforcement and communicating such policies to its external civil rights staff and funding recipients. Such policies should be aimed at providing civil rights enforcement staff and funding recipients with a complete understanding of the meaning and intent of title VI compliance relative to the specific programs HHS administers, including statements defining HHS' regulatory intent and elaborating its standards for recipient compliance. Overall, such guidance should address illegal discrimination in health care service delivery programs. In addition, it should clarify what constitutes illegal discrimination under title VI. Such guidance should be presented in the most accessible format so that it is easily understandable by those stakeholders unfamiliar with these laws and the rights and responsibilities they impose. Along these lines, the guidance might be presented in simple question and answer format and include numerous specific examples to further clarify key points.

In particular, HHS should issue policy directives on the following: (1) procedural issues particular to State-administered programs, such as HHS' block grant programs; (2) practices of inclusion for racial and ethnic minorities in HHS' programs, such as equal opportunity for participation on health and peer review boards; and (3) discriminatory practices prohibited in specific types of HHS programs, such as discriminatory criteria for obtaining research grants. In addi-

⁵¹ See chap. 3, pp. 78-79.

⁵² See chap. 3, pp. 75-76.

tion, OCR should regularly develop policy statements on emerging legal issues affecting title VI compliance, such as changes in case decisions, amendments to statutes, and revisions in regulations or policies.

Finding: One OCR regional attorney suggested that a useful means of disseminating the agency's position on specific issues is to issue well-written, well-developed letters of finding instead of traditional policy guidance. This would serve the twin purpose of providing a specific example of how a standard should be applied while at the same time taking an abstract principle and turning it into a practical, "real world" case illustrating the violation of a nondiscrimination provision in a civil rights statute. For example, OCR's Region I developed a compliance agreement several years ago in which it clearly and succinctly set forth the salient aspects of OCR's standard for assessing a recipient's defense in a disparate impact case. This is a good example of how OCR applies compliance standards in the disparate impact context and should be disseminated widely.⁵³

Recommendation: OCR should develop a "compendium" of recent letters of finding, resolution agreements, and other case-related documents and disseminate it to all regional staff. Each document should address a particular issue or compliance standard. The compendium should be indexed by statute, issue, outcome, and date. OCR should convene a task force of regional EOS and legal staff to decide what documents should be included. OCR staff should be able to use this compendium as a desk reference when developing case documents during investigations.

Defining Disparate Impact Discrimination

Finding: The HHS' Civil Rights Review Team found in 1993 that the substance of civil rights protection (i.e., what constitutes discrimination and how to discover, prevent, or remedy it) had been largely left undefined and to the discretion of each investigator, manager, reviewer, and attorney. In particular, two issues related to the theory of disparate impact discrimination need clarification through regulations or policy guidance: (1) the means of establishing the element of harm in disparate impact cases, and (2) the standard recipients must meet

in justifying policies or practices that result in disparate impact for minority individuals and communities. Both of these issues directly relate to the work of investigative staff in conducting compliance reviews and complaint investigations. They must be understood thoroughly and applied carefully to determine whether there is a violation of title VI based on disparate impact.

The insufficiency of OCR's guidance on these two issues derives principally from the lack of updated policy guidance. OCR's title VI regulations are clear in establishing disparate impact as a means of making a case for discrimination under title VI. However, OCR does not discuss in regulations or policy the applicable standards that should apply in title VI disparate impact cases. Moreover, OCR has not discussed relevant court decisions that inform an understanding of the requirements needed to show harm or the appropriate standards for assessing a defendant's claims in disparate impact cases.⁵⁴

Recommendation: OCR should update guidance to clarify its policy positions on establishing harm and assessing a recipient's claims in disparate impact cases. This guidance should provide numerous illustrative examples and fact patterns relating to these issues in a variety of contexts, including the managed care industry, the medicare and medicaid programs, and hospital relocations, in which a finding of disparate impact discrimination under the title VI regulations may be the most viable means of compelling title VI compliance. In addition, it should provide investigative staff with a current, detailed, and comprehensive discussion of the legal underpinnings—particularly relevant statutory and case law from the past 20 years—for the standards on which OCR relies in conducting enforcement activities such as compliance reviews and complaint investigations.

In addition to providing examples of policies or practices that would meet the legal standard of harm required to prove disparate impact, the guidance should also identify specific criteria for determining: (1) the legitimacy of a defendant's justification of a discriminatory policy or practice; (2) whether the defendant's policy or practice represents the least discriminatory alternative; and (3) the impact of the policy or practice

⁵³ See chap. 3, p. 86.

⁵⁴ See chap. 3, pp. 80–83.

on the ability of a population to obtain needed medical care.

As part of this discussion, OCR should implement a justification standard that is more stringent than "legitimate justification."⁵⁵ It should introduce the concept of "health care necessity," and provide a thorough discussion and analysis on the meaning and application of the term. OCR should define "necessity" narrowly, such that the disputed health care policy must *significantly* further an *important* objective; and that there are no acceptable alternative policies or practices that would better accomplish the health care purpose advanced, or accomplish it equally well with a lesser differential racial impact. This guidance should provide multiple examples of "health care necessity" as it may be used in cases involving different issues that can arise in the health care context, including discrimination arising from hospital relocations, the managed care industry, medicaid/medicare programs, or cases involving racial medical redlining, "dumping," or patients with limited English proficiency. This guidance should explain in simple, direct language, both the legal and practical aspects of the term "health care necessity," in as many contexts as possible. Such a guidance should be an effective means for OCR to provide the kind of careful, thorough investigations needed to fully ensure that complainants are served properly as well as to ensure consistent compliance among recipients.

Finding: Judges have shown a significant reluctance to find disparate impact discrimination in the health care context. In several major cases in which plaintiffs have argued that they were discriminated against because of a facially neutral policy, such as relocating a hospital from a poor area to a more affluent one, courts have appeared unwilling to rigorously apply the evidence to the appropriate legal framework. As a result, few plaintiffs have been successful in such cases. Further, there has been a chilling effect on plaintiffs' resolve to bring disparate impact cases in the health care context. Therefore, the statute and its regulations have not provided the relief from discrimination on the basis of race, color, and national origin, at least

in cases involving health care related issues, that Congress intended it to provide.⁵⁶

Recommendation: For Federal judges to better understand and more carefully consider title VI legal interpretations and Congress' legislative intent in creating title VI, OCR in partnership with the Federal Judicial Center should take steps to ensure that all Federal judges are provided comprehensive training on title VI in the health care context.

OCR should work with the Federal Judicial Center's Judicial Education Division to develop curricula for training and workshops for Federal judges on the continuing development of title VI as a means of redressing discrimination in the health care industry. This training should be conducted by experts, particularly litigators and scholars, who have worked as civil rights attorneys on title VI cases in the health care context. OCR should offer its expertise on title VI, including attorneys from OCR's Office of General Counsel, Civil Rights Division, in speaking before Federal judges and providing them with written materials to accompany training sessions. This training should address the intent and purpose of title VI with respect to discrimination in the health care industry, as well as particularly complex areas of the law. To develop and coordinate this training, OCR should enter into a partnership with the Federal Judicial Center based on a memorandum of understanding between the two agencies that would specify HHS' role in the development of training projects relating to title VI. OCR should name a liaison to work with staff from the Federal Judicial Center to develop plans for conducting at least two conferences in the year 2000. OCR should ensure through this partnership that its officials have an opportunity to address, on a frequent basis, new as well as seasoned Federal judges on title VI law.

Finding: In cases involving claims of disparate impact discrimination, some courts have increased the requirements for showing harm that constitutes a violation of title VI's nondiscrimination prohibition. For example, one court dismissed such claims, finding that health care facility policies and practices were not discriminatory under disparate impact because they "affected a comparatively small number of per-

⁵⁵ See chap. 3, pp. 83-88.

⁵⁶ See chap. 3, pp. 81-83.

sons, adequate alternative treatments were available for most, if not all, of these persons"; and "any inconvenience due to travel changes . . . [did] not rise to the level of harm necessary to enlist the equitable powers of the court." The unwillingness of these courts to accept the barriers created by health care policies and practices as evidence of disparate impact discrimination devalues the difficulties minority communities experience in gaining access to quality health care.

One commentator has observed the need for stronger empirical evidence of the impact of the movement or closure of services on the ability of a population to obtain needed medical care. Developing these measures requires the expertise of medical, social science, and other professional research staff. OCR staff have stated that they use the expertise of social science and other professional research staff working in various agency elements within HHS to assess alternatives to actions that are creating a disparate impact. However, OCR does not have any social science or other scientific experts on its staff. Moreover, OCR relies on this outside expertise on an ad hoc basis. It has no formal policy to guide its interaction with experts from other agency elements.⁵⁷

Recommendation: OCR should continue to rely as much as possible on the social science expertise of other HHS agency elements in establishing specific criteria to evaluate whether harm has been demonstrated in facility closure or relocation cases. In addition, OCR should enlist social scientists to develop criteria for establishing the element of harm in other specific health care contexts. For example, managed care organizations may be discriminating in the diagnostic tests and treatment available to medicaid patients through a process called utilization review. In this process, physicians' services are analyzed to determine whether they are medically necessary. However, the definition of "medical necessity" may be more limited when applied to medicaid patients, causing certain procedures to be authorized less often for medicaid patients than for private paying patients. OCR should work with social scientists and physicians to establish criteria for establishing the element of harm in such cases.

In order to develop a comprehensive catalogue of criteria constituting harm in a wide array of disparate impact cases, OCR should develop a formal policy to guide its interaction with experts from other agency elements. Ideally, OCR should have social scientists and physicians on its own staff to assist in the development of evidentiary standards for specific types of disparate impact cases, and to provide analysis for cases under investigation. In addition, these experts could conduct research and provide technical expertise. Short of this, OCR should craft memoranda of understanding between itself and HHS' operating and staffing divisions, that explicitly outline the circumstances under which experts would work with OCR as consultants.

Developing Model Methods of Administration

Finding: The title VI regulations include the requirement that all State recipients of Federal funds develop methods of administration (MOA). These are plans or outlines describing specific activities that a recipient will undertake to ensure compliance with title VI and prevent future civil rights violations. The title VI regulations require that MOA "give reasonable assurance that the applicant and all recipients of Federal financial assistance under such program will comply with all requirements imposed by or pursuant to this regulation." OCR issued several policy memoranda clarifying requirements for MOA in the 1970s and early 1980s. OCR may be able to serve its recipients better by issuing a new policy guidance with specific recommendations for State recipients to follow in developing their MOA. Perhaps this would help to avoid the problem of defective MOA being developed by recipients operating without clear guidance.⁵⁸

Recommendation: OCR should include in regulations or updated policy guidance clear and specific guidance for what to include among MOA, although recipients are required to develop them. OCR should use as a guide the Commission's recommendations for developing this MOA, set forth in the Commission's 1996 report on title VI enforcement and the 1966 *Compliance Officer's Manual*. Based on these recommendations, OCR should require recipients to include the following six components in their MOA: (1) designation of a full-time senior-

⁵⁷ See chap. 3, pp. 81-83.

⁵⁸ See chap. 3, p. 88.

level title VI coordinator, who reports to the Governor, to implement the State's civil rights programs; (2) a specific public outreach and education plan for notifying beneficiaries and potential beneficiaries, through public statements, written documents, meetings with community organizations and the media, of the title VI requirements that apply to federally funded State programs; (3) training for State or local program staff, subrecipients, and beneficiaries or potential beneficiaries in the Federal agency's nondiscrimination policies and procedures; (4) procedures for processing complaints, notifying the Federal funding agency, and informing beneficiaries of their right to file a complaint; (5) a program to assess and report periodically on the status of their title VI compliance that goes beyond a mere checklist of activities and assurances; and (6) detailed plans for bringing discriminatory programs into compliance within a specified period. OCR also should ensure that its investigative staff address each of these requirements thoroughly in conducting complaint investigations and compliance reviews of State or local recipients.

Title VI in Specific Contexts

Finding: To enforce the civil rights provisions for which it has responsibility, a Federal civil rights agency like OCR must go beyond developing and disseminating general policy guidance. Such an agency also must identify and confront new or resurgent areas it has not addressed sufficiently. Unfortunately, OCR has demonstrated a lack of initiative in this aspect of its enforcement role.⁵⁹

Recommendation: OCR must act decisively to provide needed guidance when social, economic and structural developments in the health care industry, such as the managed care revolution, create new potential for discrimination to occur. Such initiative is particularly needed in the contexts of illegal discrimination in the managed care industry, barriers to adequate health care associated with limited English proficiency, redlining, nursing home segregation, adoption and foster care placements, minority participation in clinical trials, race discrimination in employment and staff privileges, discrimination and affirmative action in medical

school admissions, and disparate access to organ transplantation. OCR should identify potentially discriminatory barriers to access to quality health care in each of these contexts, and should provide technical assistance and/or policy guidance to health care professionals and organizations to assist them in identifying and eliminating such barriers.

Managed Care

Finding: The potential for discrimination, particularly racial/ethnic discrimination to occur in the context of managed care is significant and is recognized as such by OCR and leading commentators and advocates for civil rights in health care services, financing, and treatment. However, OCR has done little to inform current or potential managed care organization (MCO) members, as well as MCOs, of their rights and responsibilities under title VI. OCR also has not sufficiently prepared its investigative staff to identify and confront instances of discrimination by MCOs. Despite indications of discrimination prohibited under title VI, OCR has not yet developed policy guidance specifically addressing title VI compliance in the managed care context. Interviews with OCR headquarters indicate that OCR has known about the potentially discriminatory activities of managed care organizations since 1995, yet the office has been loath to encourage or support the regional investigators in identifying cases. Both OCR regional staff and external civil rights attorneys who have litigated health care related cases have recommended strongly the need for OCR to develop policy guidance on managed care issues.

Several managed care practices can have a disparate effect on minorities. For example, one of the most common ways in which MCOs discriminate against minorities is in their selection of providers. A physician or other type of provider that serves mainly poor minorities may not be included in a managed care network because the provider's patients might be labeled "too costly." Further, some plans target suburban areas for enrollment while ignoring inner-city areas, a process known as selective marketing. In addition, some MCOs may be limiting the access of medicaid patients to the full array of providers by sending these patients provider lists that contain only providers that accept medicaid, resulting in "segregated" provider lists. Other

⁵⁹ See chap. 3, p. 88.

methods MCOs have used to discriminate against medicaid patients are excluding sections of the inner city from the MCO's service area; applying a stricter definition of "medical necessity," the standard used to determine whether a patient will receive a particular test or treatment; and longer waiting times for new-patient or urgent-care appointments.⁶⁰

Recommendation: OCR should develop comprehensive policy and investigative guidance addressing racial/ethnic discrimination in the managed care industry. Overall, this guidance should seek to inform the public, recipients, operating divisions, other HHS components, and regional investigators about racial/ethnic discrimination—both disparate treatment and disparate impact—in the managed care setting. This guidance may take the form of guidelines, or, at a minimum, a policy memorandum, published in the *Federal Register*.

In order for OCR to provide the kind of comprehensive guidance to recipients and its own staff that is needed to address adequately the implications for discrimination in managed care, OCR should include in the guidance a basic background section. In this section, OCR should provide an overview of the managed care system to provide a broad-based perspective. For example, OCR should discuss the potential problems with managed care identified by researchers and scholars, such as the emphasis on cost-containment measures. In this vein, the guidance should note that, while the advent of managed care has resulted in cost savings, it has not been a panacea for health care access and quality issues. OCR should note that not only has it failed to erase the inequities inherent in the traditional health care system, it has also brought with it new challenges, such as reduced freedom of choice, reduced access to special services, and questions about quality assurance.

In its discussion of discrimination in managed care, the guidance should communicate explicitly that exclusion of providers who serve minorities from their networks, selective marketing, segregated provider lists, and decreased services for medicaid beneficiaries are potential violations of title VI and Hill-Burton. It should address thoroughly these forms of discrimination, describing the procedures that constitute

them, how these procedures result in discrimination, and what evidence investigators should look for to identify discrimination. The guidance should use clear, concrete examples so that the composition of the unlawful behavior is clearly observable. This would not only provide practical guidance for investigators, but would afford a measure of deterrence to MCOs, as well as notice to the public about racial/ethnic discrimination by MCOs.

Limited English Proficiency

Finding: OCR recently issued a guidance memorandum intended for investigative staff that also was disseminated widely outside the agency. This guidance memorandum addresses title VI compliance specifically in the context of national origin discrimination against persons who are limited English proficient (LEP). In particular, it addresses health care service delivery for persons with limited English proficiency. Overall, the LEP guidance is a thorough, detailed document. OCR worked closely with the Department of Justice's Coordination and Review Section (CORS) staff to develop this document, and it has earned the praise of CORS for its effectiveness as an investigative guidance. It provides discussions of relevant case law, regulations, and guidelines. The memorandum maximizes its usefulness to investigative staff and outside stakeholders by elaborating on the precise meaning of a term of art such as "effective communication" and making it specific to the LEP context. In addition, the memorandum provides several general examples of the measures a recipient must take to ensure effective communication. These include: procedures for identifying the language needs of patients/clients; ready access to services for proficient interpreters in a timely manner during hours of operation; written policies and procedures regarding interpreter services; and the dissemination of interpreter policies and procedures to staff. Overall, OCR has provided in the LEP memorandum an excellent first step in establishing the program of policy development OCR has been lacking for so many years. However, there are still many important title VI-related issues that OCR has yet to address in guidance.⁶¹

⁶⁰ See chap. 3, pp. 88–92.

⁶¹ See chap. 3, pp. 92–98.

Recommendation: The Commission commends OCR for its efforts in developing this guidance memorandum. To the extent that this guidance provides clarity and precision in defining technical terminology and helpful illustrative examples, the Commission believes OCR should use this guidance as a model for future guidance on specific health care policy issues.

Finding: The language contained in the LEP guidance memorandum stating that recipients should take “reasonable steps” to ensure that LEP persons are “effectively informed and can effectively participate in and benefit from its programs” is not entirely clear. For example, the term “reasonable” is somewhat ambiguous and begs the question of what actions by recipients would constitute “reasonable steps.” Unfortunately, the guidance does not contain a section providing more clarity to these terms.⁶²

Recommendation: OCR should issue an addendum to this guidance to clarify certain terms and provide more examples and fact patterns to assist investigative staff in conceptualizing and operationalizing compliance investigation responsibilities. OCR’s investigative guidance addendum should contain an indepth discussion, using numerous specific examples to clarify for investigative staff, recipients and beneficiaries the specific meaning of the term “reasonable steps” that OCR states recipients must take to ensure that LEP persons are “effectively informed and can effectively participate in and benefit from its programs.” This discussion should state that while the meaning of “reasonable steps” may vary from recipient to recipient, the specific forms of noncompliance presented by individual recipients will vary. In this guidance, OCR also should provide examples to show how the “reasonable steps” standard will be applied to different fact patterns.

Finding: The LEP guidance indicates that a recipient should ensure that the persons it uses to provide interpretation services are competent. However, the guidance states that “[c]ompetency does not necessarily mean formal certification as an interpreter.” It also states that “it would be inappropriate to use a person who had little knowledge of medical terms or a person who spoke English poorly.” These statements reflect a significant weakness in OCR’s policy with re-

spect to persons with LEP. It is extremely important for the individuals serving as interpreters to be highly trained in both language interpreting and medical terminology. According to staff of the New York Task Force on Immigrant Health, among the serious problems that can result from using untrained or minimally trained interpreter services are: miscommunication between provider and patient on extremely important medical questions; violation of doctor-patient confidentiality; treatment of patients prior to informed consent to do so; diagnostic errors; patients’ failure to understand and adhere to medication schedules and other instructions; missed appointments; and, ultimately, negative health outcomes.

The OCR memorandum, however, sends the message to investigative staff and to recipients that compliance in the LEP context may be fully addressed without any real effort to ensure quality in the interpretation services provided. Without some form of quality assurance measure, such as proof of interpreter certification, OCR cannot ensure that persons with LEP are receiving the equal access to recipients’ programs required under title VI. However, the current guidance suggests that applying rigorous quality standards for interpreter services to all recipients is unrelated to OCR’s responsibilities to assess title VI compliance when, in fact, quality assurance measures are an integral part of ensuring equal access and nondiscrimination under title VI.⁶³

Recommendation: OCR should revise the LEP policy memorandum to include a clarification of its position on quality assurance requirements for interpreter services. OCR should emphasize the extreme importance of appropriate training, both in language interpreting and medical terminology, necessary to ensure that interpreter services operate to fully facilitate equal access and nondiscrimination for LEP persons. The policy statement should emphasize that interpretation services are a key element of compliance in the LEP context. Further, OCR should outline in this policy statement an action plan to work in partnership with other HHS agency elements and State and local recipients to ensure high-quality training for language interpreters among all health care recipients. In

⁶² See chap. 3, pp. 92–98.

⁶³ See chap. 3, pp. 92–98.

developing this plan, OCR should consider the use of medical students who possess fluency in languages other than English as a means of providing the kind of skilled, yet affordable, interpretation services that would allow many health care facilities to comply with title VI.

The LEP policy memorandum should identify acceptable options for the provision of interpreter services. For example, OCR could recommend that facilities subscribe to 24-hour telephone interpretive services which provide qualified interpreters for several languages. Alternatively, OCR could recommend that health care facilities partner with local medical schools and universities to provide onsite or on-call interpreters. OCR should encourage HHS recipients to develop creative strategies for ensuring the availability of interpreters in cost-effective ways.

Finding: The LEP guidance does not provide the level of detail necessary to assist investigative staff in making determinations as to whether compliance has been achieved. The guidance does not provide concrete examples of "as needed services" or what might constitute a "small but significant LEP population." OCR staff have stated that the lack of specificity and inadequate examples make it difficult to enforce the LEP policy.⁶⁴

Recommendation: OCR should issue a revised LEP guidance for both recipients and investigative staff providing examples of "as-needed" services or what might constitute a "small but significant" LEP population. This guidance should include a more exhaustive listing of examples with fact patterns as well as more specificity with respect to the terms denoting hospital and LEP population size.

Finding: A noteworthy weakness in OCR's LEP guidance memorandum is that it fails to include a discussion on how OCR will monitor recipients' implementation of remedial plans or resolution agreements developed in settlement negotiations with OCR. This is a matter of particular importance in large part because, as the guidance states, the barriers to access for LEP persons in the health care setting are pervasive and profound. OCR can hardly expect that recipients who commit to having interpreters present in emergency rooms are always going to fully comply. The LEP memorandum would be more

effective as guidance to investigative staff if it included a discussion on specific monitoring objectives and methods with respect to LEP-related compliance issues.⁶⁵

Recommendation: To provide more effective guidance to investigative staff, OCR should issue policy on specific monitoring objectives and methods with respect to LEP-related compliance issues. OCR also should include in this guidance a discussion detailing the actions necessary to ensure that recipients are actually implementing the policies or procedures they agree to implement as the result of the findings of a complaint investigation or compliance review. Specifically, this policy should require thorough and ongoing followup and monitoring after a compliance resolution agreement has been reached and should contain monitoring objectives and methods with respect to LEP-related compliance issues.

Finding: The LEP guidance does not carry the force of law because it is not codified in a statute or substantive regulation. In 1991 OCR developed an internal draft regulation addressing title VI national origin discrimination against persons with limited English proficiency, but failed to issue the draft regulation as a final rule. As late as 1994, the agency included this draft regulation as a proposed rule in its Proposed Regulatory Agenda published in the *Federal Register*. The proposed regulation would have prohibited certain practices including: (1) subjecting a beneficiary to unreasonable delays in the provision of services because the beneficiary has limited English proficiency, and (2) requiring a beneficiary to provide an interpreter or to pay for the services of an interpreter.⁶⁶ However, since 1994, OCR has not issued a Notice of Proposed Rulemaking or taken any other steps to further the process of developing a final rule on limited English proficiency.

The lack of a formal rule has affected OCR's ability to enforce LEP nondiscrimination obligations. For example, the LEP guidance memorandum does not forbid recipients from forcing beneficiaries to use family members as interpreters. In fact, OCR cannot require that recipients follow the policies and practices endorsed in the guidance. Because the subject matter of the guidance is not codified in a statute or substan-

⁶⁴ See chap. 3, pp. 92-98.

⁶⁵ See chap. 3, pp. 92-98.

⁶⁶ See chap. 3, pp. 92-98.

tive regulation, the guidance does not carry the force of law behind it.⁶⁷

Recommendation: OCR should issue this draft regulation as a final rule and codify it as a section of the title VI regulations in the *Code of Federal Regulations*. At a minimum, OCR should issue this draft regulation in the form of policy guidelines to recipient health care facilities.

Medical Redlining

Finding: Some home health agencies and MCOs have attempted to avoid serving inner-city areas, a practice known as medical redlining. Medical redlining disproportionately affects minorities, because inner-city areas generally are predominantly minority. OCR has provided guidance to investigators in this area by issuing a three-page document, essentially a case bulletin, that recounts one investigation, analyzes the statistical data, applies the disparate impact standard to the justification supplied by the agency, and outlines the terms of settlement of the case. It also offers tips for factfinding in future cases. The document is a good initial attempt to provide assistance to investigators on redlining.

However the document is inadequate in several respects. It is not organized in a way that makes explicit the issues, obligations, and procedures that affect recipients or investigators. For example, there are no subject headings, and aside from the last section on factfinding, there are no enumerations of required or suggested procedures. Despite its shortcomings, the guidance document does appear to touch on the paramount considerations of the redlining issue.⁶⁸

Recommendation: In light of the number of home health agencies that may be practicing redlining, and the concern expressed by several regional office staff that OCR should be doing more in this area, OCR should develop and disseminate a comprehensive guidance in the form of published guidelines or a policy document. In general, this document should be more than an investigative guidance; it should be written for both recipients and investigators. The existing bulletin should be restructured and more fully developed to create a more formal document. All

topics discussed by the current bulletin should be expanded, and some issues should be added. For example, the section that provides investigatory tips should be developed further to provide instructions for analyzing the data gathered. In addition, the document should begin with a discussion of title VI jurisdiction. OCR should provide a set of guidelines describing hypothetical situations that illustrate when a denial of service constitutes discrimination, as well as circumstances under which failure to serve minority areas would be legal. This guidance should be posted on OCR's Internet site along with addenda providing access to complete settlement agreements in redlining cases.

Nursing Homes

Finding: Civil rights compliance issues relating to nursing homes have gone largely unaddressed by OCR in recent years, despite the prevalence of segregation within the industry. The need for updated guidance for staff and recipients is borne out in examples of the serious nature of the segregation problem today. For example, the findings of a report of the New York State Advisory Committee to the Commission include data showing that although elder minorities are "among the most vulnerable members of society," they often face barriers in receiving health care and long-term care, such as in nursing homes.

OCR has addressed nursing home segregation to a limited extent through the issuance of unpublished title VI guidelines and three internal policy memoranda. Unfortunately, there are several deficiencies with these documents. First, because none of these documents was published in the *Federal Register*, they have failed to provide notice to patients and nursing homes of their nondiscrimination rights and responsibilities. Second, the guidelines and memoranda are extremely outdated: the guidelines were developed in 1969, and the most recent memorandum was issued in 1981. Third, neither the memoranda nor the guidelines sufficiently explore the issues relating to nursing home discrimination. Each memorandum is limited to a particular issue, such as whether nursing homes run by religious and fraternal organizations may exclude patients based on race. The guidelines are superficial in nature, neglecting to provide background information, or discuss legal develop-

⁶⁷ See chap. 3, pp. 97-98.

⁶⁸ See chap. 3, pp. 98-100.

ments affecting nursing home discrimination. Nor do they present hypothetical examples of discriminatory practices or acceptable alternative measures. Overall, the guidelines lack sufficient criteria and standards to measure civil rights compliance in the nursing home setting.⁶⁹

Recommendation: OCR should publish updated and expanded guidelines on the application of civil rights laws and regulations for nursing home owners and operators. These guidelines should be designed to benefit OCR investigators and patients as well. These guidelines should include a background section outlining the nondiscrimination mandate of title VI and its jurisdiction. This section should state that any nursing home that receives funds from medicare, medicaid, or any other Federal program, must abide by title VI. It should also outline the evidentiary burdens and legal standards and criteria used in determining whether a civil rights violation has occurred. Finally, the introduction should contain a narrative on the issue of nursing home segregation, including its history, causes, and relevant case law, such as *Linton v. Commissioner*.⁷⁰

The substantive section of the guidelines should remain divided into the seven functional areas identified in the 1969 guidelines, with certain adjustments. Each requirement should contain descriptions and examples of prohibited conduct and, if appropriate, acceptable alternatives. For example, the admissions requirement should state that discrimination against medicaid beneficiaries, whether by limiting the number of medicaid-certified beds, or through other tactics that delay or prevent medicaid beneficiaries from being placed in nursing homes, triggers title VI jurisdiction. The services and facilities measure should be adjusted to decrease the space devoted to the prevention of physical segregation, while according new emphasis on equal medical treatment. For example, the section should state that two patients with the same set of symptoms and medical history must receive the same examination, diagnosis, and treatment regardless of race or ethnicity. Further, the referral provision should be expanded to include examples of discriminatory referrals based upon

race or method of payment, such as the transfer of a patient to another facility based on the downgrading of the patient's required level of care, and the consequent lower reimbursement. Finally, a section describing the application of title VI to religious and fraternal organization nursing homes should be developed to benefit these types of recipients. This section should be modeled after the 1981 policy memorandum on that subject.

The final section of the guidelines should discuss enforcement by OCR. This section should describe the procedures that OCR follows when determining whether a civil rights violation exists or when conducting a compliance review. It should cite examples of potential violations and suggest the types of data to be gathered, statistical computations to be performed, witnesses and experts to be interviewed, etc. It should also explain the phases of the voluntary compliance process. The enforcement section should also address fund termination for noncompliant nursing homes.

Minority Participation in Clinical Trials

Finding: Another context OCR has not addressed in policy guidance is minority participation in clinical trials. The lack of participation may be directly related to policies and practices of federally assisted research programs, thereby potentially implicating title VI compliance. The ability of title VI enforcement to address the lack of minority participation in clinical trials is an avenue OCR has not explored. However, there are significant concerns about the effects of nonminority participation in medical research. It appears that certain clinical research practices are contributing to the racial (and gender) disparities in health care. For example, the reliance on the white male model in developing clinical research findings continues to present significant concerns about the application of such findings to treatments for minorities and women. Although OCR has not developed any guidance designed specifically to address this issue, HHS has sought to do so through guidelines issued by several of its operating divisions. For example, in March 1994, HHS' medical research arm, the National Institutes of Health (NIH), issued guidelines on the inclusion of women and minorities as subjects in clinical research. It is clear that civil rights related con-

⁶⁹ See chap. 3, pp. 101-05.

⁷⁰ 779 F. Supp. 925, 928, (M.D. Tenn. 1990), *remanded*, 973 F.2d 1311 (6th Cir. Tenn. 1992).

cerns motivated NIH and other HHS operating divisions engaging in clinical research to develop guidelines requiring minority inclusion in research trials.⁷¹

Recommendation: Through policy guidance, OCR should explore the extent to which minority participation in clinical research programs as funding recipients, participants, or beneficiaries implicates title VI, Hill-Burton, or other civil rights provisions requiring nondiscrimination on the basis of race (or gender). These guidelines should reference the earlier NIH, CDC, and FDA guidelines. They should explain the need for these guidelines and how they relate to OCR's own guidance on the issue. Further, OCR should work with NIH, CDC, and FDA to develop policies to improve methods for identifying noncompliance in this area, such as requiring the inclusion of minority researchers on peer review panels, mandating annual agency review of researchers' rosters of participants, and tracking proposals of minority researchers.

Staff Privileges

Finding: Historically, hospitals have screened out minority and poor patients through three main strategies: denying access based upon ability to pay or method of payment; failing to provide cultural, linguistic, or other accommodations for the poor and minorities; and limiting the number of physicians on staff who treat primarily minorities. Discrimination against minority physicians has been one of the most successful of the three approaches. Traditionally, it was accomplished through the denial of staff privileges to physicians that traditionally serve minority patients. Hospital staff privileges afford a physician the right to admit patients and practice medicine in an institution. This practice continues today in the hospital setting, and has also been transformed to apply in the managed care system: MCOs attempt to limit the number of minority patients they serve by excluding from their networks physicians who primarily serve minorities.

OCR has addressed staff privileges in three unpublished policy guidance documents: "Guidelines for Compliance of Hospitals with Title VI," "Guidelines for Compliance of Nursing Homes with Title VI," and "Title VI of the Civil

Rights Act of 1964 Questions and Answers," all developed in November 1969. In addition, an internal memorandum that included a brief discussion of staff privileges was issued in 1972. The objective of these policy documents was clearly to end discrimination against minority applicants to medical staffs. However, the guidelines were never published and are outdated. Having been developed in the late 1960s and early 1970s, they obviously would have no guidance relating to managed care organizations, which are now the dominant form of health care financing and service delivery. Further, they provide little title VI background information and their discussions of prohibited activities are not detailed. Moreover, they fail to acknowledge the correlation between the adequate representation of minority physicians on staffs and networks and equal access to quality health care for minority patients—the link that provides title VI statutory jurisdiction.

Surely, in 30 years OCR could have developed further insight into how to identify and prevent discrimination against minority physicians and the patients they serve. The most glaring example of OCR's failure to keep up with changes in health care is its failure to publish any guidelines for managed care organizations, which now provide health coverage for the majority of Americans.⁷²

Recommendation: It is paramount that OCR develop and publish title VI guidelines in the *Federal Register* addressing discrimination against physicians. OCR must engage in proactive leadership to eliminate continued discrimination against minority physicians and the patients they serve. OCR must educate the public, recipients, and its own staff on how to recognize and cease such conduct. In particular, OCR should publish separate guidelines for hospitals, managed care organizations, nursing homes, and other potential discriminators. In general, each set of guidelines should contain a short introductory section that explains title VI in relation to the health facility or MCO. This background section should describe the problem, articulate the purpose of the guidelines, and elucidate the link between minority physicians and minority patients, and the importance of increasing the number of minority physicians so as to improve

⁷¹ See chap. 3, pp. 105–07.

⁷² See chap. 3, pp. 107–11.

access to quality health care among minorities. It also should briefly explain the jurisdiction, standards, criteria, evidentiary burdens, and general enforcement procedures associated with title VI, the Hill-Burton Act, and the nondiscrimination provisions of block grant statutes.

In addition, OCR should include in these guidelines a description of how the statistical disparate effects analysis is conducted. This section should explain that analysis is made by examining the service area out of which the complaint originated. The statistically significant disparity is measured in relation to the area in which the defendant provides its services, offers its benefits, or conducts its business. This section should offer examples, such as the following: if a complainant were to allege a discriminatory denial of staff privileges by a hospital whose service area covers a county, then disparate impact against minorities presumably would be measured by comparing the facility's inpatient census against the proportion of racial or ethnic minority persons residing or using health care services in the county.

Each set of new or improved guidelines should list prohibited activities, such as those identified in the question and answer document. In addition, certain practices should be added, with a qualification that the practices only violate title VI if they affect minority patients disproportionately and fail the "health care necessity" test. These include such requirements for medical staff or network membership as: (1) nonacceptance of medicaid patients, (2) board certification, (3) membership in a local medical association, (4) low resource consumption patterns, and (5) location of outpatient office in a predominately white area.

The new guidelines also should outline permitted practices, or contexts in which some of the above practices would be permissible. The guidelines should emphasize that health facilities and MCOs may take certain factors into consideration, such as board certification, or resource consumption patterns, so long as they do not create disparate effects. Further, the guidelines should state that even if these considerations do create disparate effects, it may still be lawful to incorporate them into the selection process, as long as they pass the "health care necessity" test.

Finally, each of the minority physician non-discrimination provisions of the guidelines should include examples detailing prohibited practices; the information collected in an investigation; the legal standards, criteria, and evidentiary burdens applied in each case; potentially less discriminatory alternatives; and procedures for seeking voluntary compliance. For example, one hypothetical example should include an MCO that rejected a physician based upon high resource consumption patterns. The guidelines should explain how such a case would be approached by OCR. This section should educate both recipients and investigators on context-specific considerations of the investigation and enforcement processes relating to physician discrimination cases.

Organ Transplantation

Finding: An aspect of health care inequality that thus far seems to have eluded OCR's attention concerns organ donation and transplantation. A shortage of available cadaveric organs, such as kidneys, hearts, livers, and pancreases, has made obtaining needed organs difficult for all patients, regardless of race. However, in many cases, blacks suffer disproportionately from the dearth of donor organs. A complex combination of factors is responsible for the unequal access to kidney transplantation for blacks, including a shortage of kidneys available for transplant, a heightened need for kidneys on the part of the black population, applicant suitability evaluation procedures that allow wide discretion on the part of physicians, and a government-funded allocation system that relies heavily on genetic "antigen matching."

The Federal Government has taken several important steps to address the issue of equity in organ transplantation. First, Congress authorized medicare funding for virtually all kidney transplants. In 1984 Congress created a national system for the equitable allocation of organs. Two years later, Congress conditioned all medicare and medicaid reimbursement to hospitals on compliance with Organ Procurement and Transplantation Network (OPTN) policies, effectively making such compliance mandatory.⁷³

Despite the seriousness of the problem and congressional efforts to address it, as well as the

⁷³ See chap. 3, pp. 111-15.

clear potential for adverse impact and perhaps intentional discrimination in the context of organ transplantation activities, OCR has failed to develop investigative or policy guidance or to take any proactive steps to address the problem.⁷⁴

Recommendation: OCR must review the policies and procedures of the United Network for Organ Sharing (UNOS) for potential discriminatory effects, and conduct technical assistance to prevent and resolve violations. OCR should conduct limited-scope compliance reviews on UNOS, where data demonstrating the disparate effects of UNOS allocation policies already exist. OCR should consult with outside medical experts to determine whether the disparate effects are medically justified. In order to eliminate the adverse effects, OCR should provide technical assistance to UNOS in the form of assisting the organization in reevaluating the point system for kidney allocation, as well as procedures in place for the allocation of other organs. OCR should invite medical experts, policy analysts, and advocacy groups to join in the entire investigative process. The agency also should develop a policy guidance for UNOS, as well as organ procurement organizations and transplant centers, so that they are aware of the nondiscrimination mandate in the acceptance of applicants for organ transplantation. Such guidance should make clear that race should not be a factor in suitability evaluations, other than to the extent necessary to significantly further the important goal of distributing organs safely and equitably.

Medical School Admissions

Finding: The Supreme Court substantially narrowed the ambit of government-based affirmative action programs in the *Adarand Constructors, Inc. v. Peña* case of 1996. Since that decision, race-based affirmative action programs have been subject to strict judicial scrutiny, a level of scrutiny which usually results in invalidation. However, affirmative action policies based on other factors such as socioeconomic status, which may or may not use a classification such as race as a "plus factor," and not as a presumptive beneficiary, are not necessarily impermissible.⁷⁵ Moreover, regardless of the perspectives presented in certain judicial interpre-

tations of a particular time period and political bent, there is a moral imperative of a more permanent nature, an obligation, to ensure equality of opportunity in education for the economically underprivileged, many of whom happen to be racial/ethnic minorities. Medical and other professional schools need to know the legal parameters of programs intended to benefit disadvantaged groups, so that medical and professional schools can develop sound policies.

OCR has also failed to provide policy guidance on discrimination in medical school admissions and study its effect on equal access to quality health care for minorities. A review of literature and case law addressing efforts to increase minorities among students admitted to professional school suggests two broad themes. The first is the need for OCR to establish clear guidelines on affirmative action plans and to address more fully through policy and enforcement activities the issues of discrimination in minority admissions to medical schools, and the need to take remedial action to overcome it. The second theme is the need for HHS/OCR to work with DOEd/OCR to ensure that minority students in elementary and secondary schools are provided with the tools necessary for them to compete successfully with their nonminority peers at the college and professional school levels. This collaboration will allow the agencies to move in a new direction in their efforts to increase the number of minority students who pursue careers in medicine.⁷⁶

Recommendation: Of all programs assisted by HHS funds, medical schools are certainly one of the most crucial from a civil rights perspective. OCR must develop the kind of comprehensive, detailed policy guidance that can provide medical school administrators with the information they need to ensure that they are complying with nondiscrimination mandates *and* undertaking proactive efforts to ensure equal access to education in medicine for racial/ethnic minorities and women.

OCR should provide clear guidance for medical school recipients. OCR should develop an introductory section based on the data presented by numerous government reports, private commentators and researchers, and statistics demonstrating the important role of affirmative ac-

⁷⁴ See chap. 3, pp. 112–15.

⁷⁵ See 515 U.S. at 237.

⁷⁶ See chap. 3, pp. 115–27.

tion and diversity programs at universities and graduate and professional schools in expanding equal access for *all* medical students and, ultimately for health care service to minorities and women. This discussion should set forth as much data and commentary as possible on the need for title VI compliance among medical schools to illustrate clearly the racial/ethnic disparities that continue in the medical professions, and the negative effect these disparities reveal on access to quality health care for minorities.

OCR must provide guidance to medical schools on how it evaluates whether a school has been discriminating in its admissions programs. OCR must develop this guidance to ensure that medical schools are fully aware of their obligations under title VI, particularly the implications of such factors as past discrimination. OCR's guidance should review the relevant case law and its implications for title VI compliance and ways in which medical schools can develop policies to comply with title VI and its regulations.

HHS/OCR should work with DOEd/OCR to ensure that minority students in elementary and secondary schools are provided with the skills to compete with their nonminority peers at the college and professional school levels. The two agencies should collaborate on guidelines for medical school admissions and the use of affirmative action policies.

Finding: One potentially effective vehicle for addressing the issue of discrimination and the need for affirmative action programs in medical school admissions is OCR's title VI regulatory guidance. These regulatory provisions identify affirmative action as a means of "administering a program regarding which the recipient has previously discriminated" and "overcoming the effects of conditions which resulted in limited participation."⁷⁷ However, OCR has issued no policy guidance providing sufficient clarity on the meaning of these terms. Moreover, OCR has not provided any guidance on the standards it will use to evaluate medical schools' admissions policies, both those that have affirmative action-based policies and those that do not have such policies. OCR is not fulfilling its responsibilities to clarify the requirements of the provisions in the title VI statute and its regulations, despite its duty, as one commentator has said, "to give

⁷⁷ See chap 3, pp. 124-25.

examples of prohibited practices in the context of particular programs, to outline required and suggested remedial action . . ."⁷⁸

OCR also has not addressed in policy guidance standards for evaluating the constitutionality of affirmative action programs created by a recent court case, *Texas v. Hopwood*, in which a three-judge panel of the U.S. Court of Appeals for the Fifth Circuit found a professional school's admissions policies impermissible under the equal protection clause.⁷⁹ In the *Hopwood* case, brought by individuals claiming race discrimination resulting from an affirmative action policy, the fifth circuit significantly narrowed the ambit of the term "past discrimination" in a fashion that one commentator has referred to as straining "the bounds of reason and prevailing precedent."⁸⁰ Under *Hopwood*, the only remedial racial classifications that could be justified would be those employed to redress present harm resulting from past discriminatory practices by the law school itself, rather than other "units" within the Texas public school system.⁸¹

Recommendation: OCR's policy guidance on discrimination in medical school programs and remedial plans to help eradicate discrimination should clarify the meaning of the term "affirmative action" as it relates to HHS-funded medical school programs. OCR also must clarify the requirements of the "affirmative action" provisions in its regulations. OCR should use these standards to evaluate medical schools' admissions policies, both those that have affirmative action based-policies and those that do not. In particular, OCR should define clearly, within the parameters set by case precedent, the term "affirmative action" itself, as well as "past discrimination," "limiting participation," and "diversity." It should note that the terms "affirmative action" and "quota system" are in no way synonymous; nor is there any requirement in OCR's title VI regulations for recipients to rely on quota systems in developing affirmative action policies. This guidance should include illustrative examples of the most effective ways to develop diversity and affirmative action programs.

⁷⁸ See chap. 3, p. 125.

⁷⁹ 78 F.3d 932 (5th Cir. 1996).

⁸⁰ See chap. 3, pp. 122-24.

⁸¹ See chap. 3, pp. 122-24.

OCR must provide guidance to medical schools on how it evaluates whether a school has been discriminating and how it determines whether an affirmative action plan meets constitutional standards. Essentially, OCR should include guidance identifying criteria for determining whether a program is permissible. OCR should provide examples of cases where the courts have found particular institutions to have engaged in prior discrimination, so that all medical schools will better understand the extent of their obligations under the title VI regulations. Therefore, OCR must address the narrow ambit carved out by the courts for developing and implementing affirmative action and diversity programs. OCR's guidance should address cases that may help to shape the standards OCR will apply in evaluating title VI compliance in the medical school admissions context. For example, OCR should address standards created by the *Texas v. Hopwood* case for evaluating the constitutionality of affirmative action programs.

In addition, OCR should address another factor relating to recent judicial interpretations of affirmative action programs: the constitutionality of the second of OCR's two affirmative action provisions in its title VI regulations in the context of State-run institutions; and the reach of the regulations for private medical schools receiving Federal funding. For example, it appears that almost any affirmative action plan undertaken by a school without sufficient evidence of a past history of discrimination by that school would be invalidated under the Constitution. Therefore, the constitutionality of the second of OCR's two affirmative action provisions in its title VI regulations probably would be called into question if subjected to a judicial interpretation.

In developing this policy guidance on medical school admissions, OCR would not be the first Federal civil rights enforcement agency to issue guidance on affirmative action programs. For example, in 1994 the Department of Education (DOEd) issued policy guidance, published in the *Federal Register*, addressing the applicability of the title VI statute's and regulations' nondiscrimination requirements related to student financial aid that is awarded, at least in part, on the basis of race or national origin.⁸² Although this guidance will probably need revisions as a

result of recent case law, it provides an excellent example of the kinds of issues HHS/OCR should address, in consultation with DOEd's Office for Civil Rights (DOEd/OCR). At a minimum, HHS/OCR should refer to the DOEd's OCR guidelines on affirmative action in preparation of its own title VI affirmative action and diversity guidelines.

Finding: Recognizing the vital role minority physicians play in the delivery of health services to economically disadvantaged and minority populations, several medical schools are trying to increase the enrollment of minority medical students. Many of the institutional initiatives are innovative and effective, and at the same time are relatively simple in design and implementation, which makes them excellent models to be replicated by other programs.

One example of a model program is the University of Michigan, which recently brought together a team of leading scholars to study the need for racial, ethnic, and cultural diversity in higher education. According to the University, its empirical analysis showing the benefits of diversity indicates that "patterns of racial segregation and separation historically rooted in our national life can be broken down by diversity experiences in higher education." The university's findings suggest that higher education programs seeking such diversity may be breaking down barriers to integration, nondiscrimination, and equality of opportunity in all facets of life experience, including access to quality health care.⁸³

Recommendation: The Commission commends the many examples of creative and innovative efforts to ensure diversity by institutions of higher education. OCR must ensure that medical school recipients are fully aware that the title VI regulations include provisions on affirmative action. Moreover, in collaboration with the U.S. Department of Education Office for Civil Rights, HHS/OCR must ensure that top administrative and other decisionmaking personnel at these schools fully understand OCR's objectives in encouraging proactive efforts to include minorities and women among their student populations. OCR therefore must include in its guidance to medical schools a discussion on: (1) the kinds of affirmative action programs that

⁸² 59 Fed. Reg. 8,756 (1994).

⁸³ See chap. 3, pp. 118-19.

are permissible; (2) the acceptable rationale for conducting affirmative action based admissions programs; (3) the scope for evaluating the effects of past discrimination; and (4) the evidence required to show past discrimination, e.g., disparities in numbers of racial/ethnic minorities represented in the student population. In particular, OCR should address more current ideas for implementing affirmative action programs, such as recruiting economically disadvantaged students, with race-based presumptions in identifying disadvantaged individuals.

Hill-Burton Act: Overall Lack of Policy Development

Finding: HHS has provided regulations for the Hill-Burton Act pursuant to a provision in the statute. The act's nondiscrimination provision, known as the community service assurance provision, is contained in these regulations. The provision states that all recipients of Federal funds under the Hill-Burton program must provide service "without discrimination on the ground of race, color, national origin, creed, or any other ground unrelated to an individual's need for the service or the availability of the needed service in the facility."⁸⁴ This is one of two provisions in the Hill-Burton regulations with a nondiscrimination requirement. The second provision requires nondiscrimination against beneficiaries of government third-party payers. OCR has not issued any policy guidance on Hill-Burton related enforcement issues in many years. For example, one commentator contends that the provision requiring nondiscrimination against beneficiaries of government third-party payers "has never really been used. There is no policy guideline, so it's never been enforced. OCR has no familiarity or expertise with it."⁸⁵ Despite the lack of recent policy guidance, to its credit, OCR did issue a policy guidance in 1981. More recently, OCR developed a draft chapter discussing Hill-Burton enforcement in its draft substantive compliance manual. However, this document will remain in draft form for perhaps as long as 2 years.⁸⁶

Recommendation: OCR should immediately develop an appendix to its Hill-Burton

regulations providing interpretive guidance on the nondiscrimination provisions. This guidance should provide more detailed analyses and examples than are currently provided and should update, where applicable, the policy guidance issued in 1981. In particular, a discussion addressing the term "any other ground unrelated" would be useful since it appears to go beyond the scope of title VI. In addition, OCR should develop updated guidance on the provision requiring nondiscrimination against beneficiaries of government third-party payers. OCR also should issue the Hill-Burton chapter of its substantive compliance manual as soon as it is complete, rather than waiting for the entire manual to be finished before releasing any section of it.

Hill-Burton: Antidumping

Finding: OCR has made two efforts to provide guidance to investigators on patient-dumping cases. OCR issued a detailed instruction packet to its regional staff in 1988, and has developed a chapter on the subject for its draft substantive compliance manual. The packet provided a wealth of materials to assist investigators in processing dumping complaints and compliance reviews. The packet provided a framework for processing and investigating dumping cases from receipt of the complaint to case closure. It elucidated the jurisdictional issues used to determine whether OCR may investigate complaints, and outlined the elements affecting the referral of cases to the Health Care Financing Administration (HCFA) and the HHS Office of Inspector General (OIG). The Model Investigative Plan recommends the specific information to be gathered by investigators, along with potential sources, and describes how such information should be applied. The comprehensiveness of the dumping instructions illustrates the high quality that OCR can produce for high-profile issues. If other policy could be promulgated with the same depth of thought and attention to detail, OCR regional staff would have sound guidance in all areas of investigation.

In comparing the 1988 guidance with the draft subchapter, OCR's 1988 instructions to investigators appeared effective as guidance on the antidumping issue. The data gathering suggestions provided thorough explanation of the data to be collected, and how they should be used. By contrast, OCR's more recent draft subchapter on

⁸⁴ See chap. 3, pp. 127-28.

⁸⁵ See chap. 3, p. 128.

⁸⁶ See chap. 3, p. 128.

this issue in its draft substantive compliance manual lacks such specificity. It fails to provide information on the coordination of these cases among OCR, HCFA, and OIG, which share jurisdiction in many dumping cases. Neither does the chapter detail the types of evidence necessary to analyze such cases, the sources of evidence, nor how such analysis should proceed.⁸⁷

Recommendation: OCR should revise its draft subchapter on patient dumping to include elements that are contained in the dumping instruction packet of 1988. The subchapter should include a section on case processing that describes how dumping case investigations should be coordinated among OCR, HCFA, and OIG. It should also provide more instruction on specific types and sources of evidence to be used by investigators, as well as how to analyze the documents or evidence. Examples should accompany this discussion. Further, the remainder of the Hill-Burton chapter of the draft substantive compliance manual should also be expanded to include more guidance on data collection and analysis.

Finding: Overall, the antidumping subchapter confronts the major points of concern for its topic. It describes the prohibitions of the antidumping section of the Hill-Burton regulations, attempting to anticipate and clarify potential areas of confusion. Further, it describes the basic process of emergency intake and treatment at most facilities. Finally, it suggests lines of questioning and possible data sources. However, in addition to its failure to provide guidance on the coordination of dumping cases, and the absence of comprehensive factfinding suggestions, the subchapter is lacking in background information and definitions.

First, the subchapter falls short of describing in detail the context in which dumping occurs, and the factors that can lead to dumping. Investigators need to understand how health professionals remain disengaged from emergency patients, and how this may affect their judgment in determining what treatment is necessary. Another important element lacking in the draft subchapter is a precise definition for the term "emergency." The generalized definition in the draft leaves too much to the discretion of triage nurses. It allows them too much leeway in deciding whether a patient's symptoms are require

immediate attention, creating increased potential for discrimination based upon either race or inability to pay.⁸⁸

Recommendation: In revising the draft subchapter, OCR should develop a background element illustrating the context in which emergency services occur, and the factors that can lead to patient dumping. OCR should provide examples of these factors, such as psychosocial elements that impinge upon a triage nurse's ability to objectively rank patients in the emergency queue, including race or social class. OCR should also address the definition of an emergency. OCR should expand on the basic definition it already has provided by analyzing issues that can complicate the determination of what constitutes an emergency, such as the use by some health care facilities, particularly managed care organizations, of different definitions of emergency than what is required by Hill-Burton regulations. In addition, while it would be difficult to develop a lengthy catalogue of symptoms that would constitute an emergency, there may still be approaches for implementing more definite standards. If an emergency medical manual were selected as the standard, this would supply more specific benchmarks for investigators to use in their work. Expert physicians from other HHS agencies could assist in interpreting the emergency medical manual for the investigators.

Title IX: Overall Lack of Policy Development

Finding: HHS/OCR shares enforcement responsibilities for title IX with the Department of Education OCR. The two agencies do not have a memorandum of understanding (MOU) relating to the coordination of title IX enforcement. Such an MOU could provide significant benefit to the title IX enforcement efforts of both agencies. An effective MOU would eliminate duplication of enforcement efforts in complaints and compliance reviews.⁸⁹

Recommendation: HHS and DOE should enter into an MOU to ensure more effective title IX enforcement efforts by both agencies. This MOU should clarify the roles of each agency in enforcing title IX. It should delineate clearly the enforcement activities that each will conduct with respect to title IX.

⁸⁸ See chap. 3, pp. 128–33.

⁸⁹ See chap. 3, pp. 133–34.

⁸⁷ See chap. 3, pp. 128–33.

Finding: OCR's efforts in title IX enforcement in the health care context have been pathetic. Although HHS has enforcement responsibilities for the statute, it has not developed policy guidance, performed compliance reviews, or conducted technical assistance, outreach, or education regarding title IX. OCR staff assert that there are very few title IX complaints filed with HHS. However, part of the reason for this absence of complaints could be that OCR has not been proactive in identifying instances of title IX discrimination. For example, the underrepresentation of women in medical research projects, both as subjects and as researchers, recently has received a great deal of attention from scholarly commentators, the news media, Congress, and HHS itself. Practices that have the effect of excluding women from federally funded medical research in higher educational institutions potentially violate title IX. Another issue relates to the difficulties women confront in pursuing medical study and practice, such as stereotypes that steer women to fields traditionally associated with women, such as nursing, pediatrics, and other primary care areas.

The need for some form of policy and/or investigative guidance on title IX is underscored by the Commission's finding that some senior regional investigative staff were unaware that OCR had developed regulations under title IX and were generally unfamiliar with OCR's enforcement responsibilities under title IX. In interviews with Commission staff, these regional staff members stated repeatedly and emphatically that they were not aware of regulatory guidance by OCR on title IX. This lack of awareness about such a fundamental component of OCR's work is a strong indicator of the need for policy and investigative guidance addressing OCR's responsibilities under title IX.⁹⁰

Recommendation: In collaboration with DOEd/OCR, HHS/OCR should develop at least one policy guidance on title IX in the context of health care. This guidance should be an effective mechanism for training OCR staff and educating funding recipients about what might constitute a violation of title IX and how compliance can be effected in specific circumstances. OCR should develop this guidance in the form of a policy memorandum to regional directors. This policy

guidance should describe the legislative history of the statute, its regulations, and any relevant legal cases or administrative proceedings. This guidance also should contain hypothetical examples of title IX compliance issues in the health care/medical context, perhaps addressing title IX violations present in medical school admissions and research programs. In addition, OCR should focus more of its resources on ensuring compliance with title IX through outreach, education, and technical assistance efforts, and compliance reviews.

Nondiscrimination in Block Grant Statutes

Finding: As with title VI, Hill-Burton, and title IX, OCR has been loath to exert any significant effort in developing regulations or policy guidance relating to the nondiscrimination provisions in block grants. OCR has not published regulations or policy guidance regarding those provisions. The only example of guidance the Commission has found is an internal guidance document prepared by OCR's Region X, called "Policy on Investigative Complaints Based on Sex and Religion." However, this document is inadequate as policy guidance. It provides very little information, no contextual discussion to clarify the coverage of the nondiscrimination provisions, and no illustrative examples of cases that have or might arise based on these provisions.

The document provides two statements as guidance for investigative staff. The first informs investigative staff that a complainant "must articulate a clear violation of the statute."⁹¹ The second statement in the Region X guidance notes that "[t]he office will investigate only those entities (program or activity) that receive federal funding from block grants which prohibit discrimination based on sex or religion."⁹² Neither statement is clarified further. The guidance also states that as a first step in reviewing complaints, the investigators should determine whether the office has title IX jurisdiction in addition to block grant jurisdiction.⁹³ This is a key issue and should be far more developed than it is in this document.

Recommendation: OCR headquarters should develop a comprehensive policy guidance document on sex and religion designed for the

⁹⁰ See chap. 3, pp. 133-37.

⁹¹ See chap. 3, pp. 137-38.

⁹² See chap. 3, pp. 137-38.

⁹³ See chap. 3, pp. 137-38.

benefit of both HHS funding recipients and OCR investigative staff. This policy guidance should provide instruction on what constitutes a violation of the various block grant statutes and the criteria to apply in assessing the presence of a violation. This policy guidance should provide a contextual discussion clarifying the coverage of the nondiscrimination provisions, and containing illustrative examples of cases, actual or hypothetical, that illustrate the kinds of compliance issues that can arise.

The guidance also should identify the appropriate standards to apply in determining whether there has been a violation based on sex or religion. In particular, this discussion should address from a compliance perspective the definition of the term “program or activity,” and should discuss the different block grants programs and their recipients. Also, this guidance should contain a fully developed discussion on the interaction between title IX, which also provides for nondiscrimination on the basis of sex, and the block grant provision statutes providing the same.

Chapter 4. Ensuring Civil Rights Compliance: OCR’s Enforcement Efforts Summary

The Office of Civil Rights’ (OCR) enforcement activities reflect the same halfhearted approach that affects its policy development efforts. The office collects data sporadically and without scientific rigor; its investigations rarely uncover evidence of violations; and it has neglected to collaborate with State agencies to devise and oversee State recipients’ methods of administration. Another key indicator of the ineffectual and lethargic nature of OCR’s compliance and enforcement operations is the lack of expertise the agency exhibits in conducting enforcement procedures such as preaward and postaward compliance reviews and complaint investigations.

The Department of Justice (DOJ) regulations require Federal agencies to collect and maintain data that is sufficient to determine whether recipients of Federal funds are in compliance with civil rights provisions. However, Health and Human Services (HHS) has not implemented a satisfactory data collection system. For example, the triennially distributed Hill-Burton community service assurance reports collect racial information only for Hill-Burton hospital inpa-

tients and emergency room patients. Data are not collected concerning patients’ doctor visits, which are vital to determining whether patients receive the same quality of medical treatment, regardless of race, ethnicity, or gender.

A final source of frustration concerning the office’s efforts at data collection is its isolation from other HHS data collection efforts. For instance, OCR has failed to ensure appropriate data collection on race/ethnicity in the medicare/medicaid program administered by the Health Care Financing Administration (HCFA). This reflects a failure on the part of HCFA and OCR to recognize that medicare and medicaid present a significant number of potential civil rights implications. However, HCFA has not been subject to any kind of scrutiny by OCR with regard to collecting such data. To date, HHS and OCR have failed to implement a more thorough data collection system that would incorporate collection of race data in all health care programs.

The Commission also is concerned with OCR’s neglect of racial discrimination issues under title VI, despite a wealth of research showing the disparities in health status and access to quality care and treatment between whites and racial/ethnic minorities. For example, the Commission’s review of OCR’s letters of finding and other case closure documents, as well as regional monthly significant activities reports, indicates that, since 1997, OCR has uncovered few violations on the basis of race in the health care context. Overwhelmingly, OCR has found the recipients to be in compliance in complaints in which the allegation(s) of discrimination against the recipient are based on race. OCR’s enforcement process subscribes to a “piecemeal” case management philosophy that minimizes the seriousness of infractions and eschews systemic compliance issues. The agency’s emphasis on preaward desk audits of medicaid recipients monopolizes a substantial proportion of OCR resources, effectively crowding out indepth complaint investigations and compliance reviews. Moreover, the superficial character of these desk audits prevents staff from uncovering a significant number of systemic violations.

Further, when complaint investigations or compliance reviews do occur, OCR staff may not possess the knowledge and experience to conduct them successfully. When OCR does discover a potential violation during a complaint investiga-

tion or compliance review, its primary objective appears to be to negotiate settlement between the recipient and complainant, rather than continuing the investigation to determine the extent to which the recipient's conduct has affected other beneficiaries. The Commission commends OCR for its attempts to settle appropriate cases. However, without actually conducting investigative procedures, developing findings, writing investigative reports, or performing monitoring activities, OCR investigative staff have little opportunity to learn, use, or improve their investigative skills. Unless OCR takes affirmative steps to ensure that staff maintain these skills, a devolution of standards for investigative work will result. In addition, a review of OCR's case closure letters and other documents indicates a lack of rigor in both investigative procedures and legal analysis. Moreover, the apparently often ineffectual nature of OCR's investigative staff training is evident in the subpar quality of investigative techniques and methodology as described in letters of finding and observed in interviews with regional staff. For example, the letters of finding indicate little understanding of fundamental approaches to identifying and preventing discrimination in the health care context.

The complaint filing process itself is not conducive to the identification of possible violations due to the logistically unrealistic nature of some of the procedural requirements for complainants. For example, OCR imposes a 15-day limit on the complainant to provide all details pertaining to the allegations in the complaint, including remedies sought and information sufficient for OCR to understand the basis of the complainant's charge of discrimination. If a complainant fails to provide the necessary information within the allotted time, OCR will close the complaint. This 15-day requirement seems an onerous burden to place on the potential complainant, both with respect to the brevity of time allotted and the sanction for not complying fully in that time. Further, the language describing the required complaint information is somewhat technical and may not be understood by a person inexperienced with these procedures.

Compliance reviews, which are the most effective tools for identifying large-scale systemic discrimination, are underutilized. OCR's *Case Resolution Manual* (CRM) neither articulates adequately the importance of compliance re-

views, nor appropriately distinguishes them from compliant investigations. For example, although the CRM states that the purpose of a compliance review is to ensure systemic compliance, it fails to define "systemic compliance" or describe how compliance reviews can achieve conformity. Further, the CRM, which is the primary source of investigative guidance, avoids *any* discussion of investigative procedures or case resolution methods particular to compliance reviews. Surely, a violation at the systemic level should be resolved differently from an infraction that affects only a single complainant. The failure of the CRM to accord the proper degree of attention to compliance reviews demonstrates the low regard in which they are held. The small number of comprehensive full-scope compliance reviews performed by each regional office also suggests this perception. Generally, each regional office conducts fewer than five full-scope compliance reviews per year. One regional office failed to list a single full-scope compliance review in its annual operating plan for 1998.

Similarly, OCR has neglected to effectively incorporate issues related to State recipients of HHS block grant funds and their subrecipients in its civil rights compliance activities. Because millions of dollars from HHS program funds are disseminated to local agencies and organizations through the States, there is the potential for federally subsidized discrimination at the local level. Department of Justice coordinating regulations instruct State recipients of Federal funds to develop methods of administration to ensure that continuing State programs remain free of discrimination. However, this requirement does not dissolve the responsibility of OCR to ensure that State recipients and subrecipients operate their programs in a nondiscriminatory manner.

OCR's attention to States' methods of administration (MOA) has been uneven, with some regional offices providing information on and reviewing MOA while other regions have failed to provide assistance to States with their MOA. Further, HHS has not implemented an effective monitoring system to ensure that States or their subrecipients are complying with civil rights laws. OCR does not review States' compliance policies, programs, and activities on a regular basis, and it does not require States to report on their own compliance activities or those of their subrecipients. In addition, OCR regional staff do

not systematically collect data with which to ascertain civil rights compliance.

Another element of civil rights enforcement and oversight involves technical assistance, outreach, and education. HHS/OCR headquarters and regional offices are responsible for providing civil rights technical assistance, and outreach and education activities, including civil rights training, dissemination of civil rights information, and guidance and assistance on applicable civil rights laws and initiatives. These activities and programs are to be offered to other HHS staff, recipients and recipient groups, State and local officials, beneficiary organizations and institutions, and other advocacy groups.

Although OCR headquarters recognizes the importance of these activities in their operations, there has been little effort made to implement departmentwide programs, nor have there been efforts to provide guidance to regional offices on conducting these activities. When these programs are initiated, OCR, for the most part, uses outdated documents for the statutes, including title VI. In addition, OCR underutilizes technology as a resource, provides these activities on an ad hoc basis, addresses a limited number of issues, and implements these activities without formal standards or guidelines. OCR attributes the minimal amount of technical assistance, education, and outreach to the limited amount of resources allocated for such activities. However, these budget constraints appear to have affected title VI and Hill-Burton more than other statutes and initiatives. Within the past 4 years, OCR has been able to provide updated and detailed information on section 504, as well as offer written guidance on LEP, welfare reform, and other departmental initiatives.

Within the regional offices, technical assistance, education, and outreach vary. Resources dictate where and how often these activities take place (often in the central city of a region), who receives the assistance and education, and who is responsible for conducting these activities (ranging from the regional manager in one office to the entire staff in another). In some cases, OCR regional staff participate in operating divisions' and other organizations' conferences and activities to get the civil rights message out. In addition to the fact that these activities are not performed evenly across regions, regional staff are

not provided adequate, updated training so that they can provide relevant guidance to the public.

Data Analysis

Finding: HHS' title VI regulation directs recipients of HHS funds to keep records and submit accurate compliance reports when requested. The regulation provides only one example of the type of statistical information that recipients should make available when requested by HHS—the racial/ethnic composition of program participants/beneficiaries. In addition, the regulation does not specify any particular time-frame in which the recipient must submit the information to HHS once requested. The regulation does not impose a standard, since it authorizes HHS to request and receive from recipients the particular types of information which the Department arbitrarily deems necessary. Thus, HHS is entitled to require different types of racial/ethnic data, depending on the type of review, investigation, or other individual circumstance. This regulation, similar to other HHS regulations implementing title VI, is broad and does not include substantive guidelines for HHS to follow when deciding what data to collect, maintain, and analyze and under what circumstances.

In a recent Federal court case, *Madison Hughes v. Shalala*,⁹⁴ health care advocacy groups argued that HHS regulations require the agency to collect patient- and provider-specific data from recipients as part of its title VI enforcement efforts. At issue was the Health Care Financing Administration (HCFA) billing form, HCFA-1450, which is used to collect information on each transaction between a medicare or medicaid patient and a health care provider. The HCFA form 1450 (or form A 837) collects information about medicare and medicaid patients, such as patient name, address, birthdate, gender, dates of service, diagnosis codes, treatment authorization codes, specific services provided and respective dates, total charges and noncovered charges, and physicians' signatures. The plaintiffs in the case argued that the form should be altered to collect data on the race and ethnicity of patients.

The plaintiffs in *Madison Hughes*, as well as many health care interest groups, believed that the inclusion of a race data element to the form

⁹⁴ 80 F.3d 1121 (6th Cir. 1996).

would greatly improve efforts to detect instances of race discrimination against patients. However, the plaintiffs' case failed, and HCFA was not required to modify its form. Neither were advocates able to persuade HCFA to do so voluntarily, although it remains undisputed that HCFA possesses the *authority* to do so, should it choose. This bureaucratic decision nullified what was potentially one of the most effective solutions to the problem of documenting discrimination by health care providers. Moreover, adding this information would not be overly expensive for HCFA, or overly burdensome for the insurers that complete the forms.⁹⁵

Finally, OCR regions do not maintain data on the names or the total number of HHS recipients within the region. For example, according to OCR regional staff, OCR's current database does not retain any information on a consistent basis for HHS recipients, except for medicare providers who receive reimbursement funds from HCFA.⁹⁶

Recommendation: OCR should commence routine collection of the demographic data necessary for determining and evaluating racial/ethnic minority communities' access to federally financed health care, and the health care services they receive. In particular, OCR, the Secretary, and the Surgeon General should exert pressure on HCFA leadership to add data identifying race/ethnicity of patients to HCFA-1450 and A 837. Further, HHS should adapt existing databases to include a race "field." The data collected should include enrollment, utilization, outcome, health care provider certification, and consumer satisfaction among these communities. OCR also should institute a comprehensive information collection system aimed at ensuring that funding recipients, such as medicare providers or Hill-Burton program recipients, are fulfilling their title VI compliance obligations. Information should be collected that assists OCR in ascertaining deficiencies, such as the discriminatory practices, in funding recipients' administration of all HHS' programs.

HHS/OCR should partner with HHS' Office of the Assistant Secretary for Planning and Evaluation to develop formal guidelines, published in the *Federal Register*, specifying the

data elements that are necessary for determining applicants' and recipients' compliance with title VI. The data elements identified in the regulations should include: (1) the manner in which services are provided by the program; (2) the race, color, and national origin of the population eligible to be served; (3) data on covered employment, including the use of bilingual employees to work with beneficiaries who do not speak English; (4) the location of existing or proposed facilities and information on whether the location will have the effect of denying access to any person on the basis of prohibited discrimination; (5) the race, color, and national origin of the members of any planning or advisory body that is an integral part of the program; and (6) requirements and procedures designed to guard against unnecessary adverse impact on persons on the basis of race, color, or national origin when relocation is involved.

The guidelines should recommend that HHS/OCR compare the racial and ethnic composition of actual and potential program participants, to determine if any particular racial/ethnic group is admitted to a facility or treated or served in a health care program in a different manner, such that further investigation is needed. The guidelines should also specify that applicants and recipients must submit to HHS the specified necessary information within 30 days after receiving the request for information or within the particular number of days indicated on HHS' written request for information, or within a number of days negotiated verbally between HHS and applicants/recipients.

CSA Report

Finding: The Community Service Assurance (CSA) reporting system currently is OCR's only method for routinely collecting data. However, the CSA only includes recipients of funds for medical facility construction under the Hill-Burton Act. In 1996 OCR also conducted a survey of non-Hill-Burton hospitals, but these facilities are not routinely required to provide data to OCR.

The CSA reports currently identify the race/ethnicity of beneficiaries in only two general areas: inpatient admissions and emergency services. Consequently, facilities that provide only outpatient or clinical services, such as a public health clinic or certain rehabilitation centers, would not be reporting any racial/ethnic

⁹⁵ See chap. 4, pp. 141-45.

⁹⁶ See chap. 4, pp. 152-53.

data on beneficiaries served or program participants. Overall, the CSA report does not ask any facility to report on the racial/ethnic or gender composition of recipients of specific health care services and procedures. Therefore, the form cannot reveal whether members of different racial and ethnic groups or women are treated disparately, and are thereby receiving the various inpatient, outpatient, clinical, and community services and procedures offered by a health care facility on a disproportionate basis.⁹⁷

Further, data on the CSA form are collected only once every 3 years. Because facilities self-identify their service areas, statistical analyses based on the data collected may be inaccurate. Thus, OCR staff use the data collected only as a targeting instrument, and must also use other information to identify facilities for compliance reviews.⁹⁸

Recommendation: The CSA form should ask each Hill-Burton facility, not solely those that provide emergency and/or inpatient services, to report on the racial/ethnic and gender composition of recipients of its specific inpatient, outpatient, clinical, and community services, as well as services received. In addition, each Hill-Burton facility should report the racial/ethnic or gender composition of the geographic area surrounding the health care facility.

However, given that the CSA form is submitted only once every 3 years and only by Hill-Burton facilities, OCR should consider adopting a different strategy for collecting data for the purposes of identifying potential violations of title VI, the Hill-Burton Act, title IX, and other civil rights statutes. To be more inclusive, HHS should require that its funding recipients submit this data to OCR on an annual basis. Alternatively, OCR should administer a survey to a representative sample of all health care facilities receiving HHS funds to determine compliance with all civil rights statutes. Further, the survey should identify problem areas within the industry to which OCR should pay more attention in providing technical assistance and outreach.

A Unified System of Data Collection

Finding: There is a vast array of health information being collected by health care provid-

ers, private organizations, and governments at all levels, but there is currently no organization that coordinates the information, nor is there a national health care database. Most State agencies and health care providers collect data on patients and services provided. Such data are collected primarily for the purpose of assessing health status and conducting research on at-risk populations. In addition, health care organizations, such as health maintenance organizations, maintain administrative and billing information on patients and services provided. Further, several HHS nationwide surveys collect health care related information. However, because of the lack of coordination among them, the data collected by these agencies and organizations is both duplicative and inadequate for determining whether the Nation's health care system provides equal access to quality health care.⁹⁹

Recommendation: To ensure that all health care related information is collected in a consistent manner that protects privacy and confidentiality, a centralized system for health data collection must be implemented. The Commission concurs with the 1993 recommendation by the Institute of Medicine's Committee on Monitoring Access to Personal Health Care Services, that one organization should be responsible for the central collection, analysis, improvement, and dissemination of information on access to health care. This organization would monitor both access to and quality of health care for all Americans. In addition to monitoring, the Commission recommends that this agency assume other duties related to civil rights in health care. The Commission recommends further that the agency be quasi-governmental, to minimize the risk of politicization.

The agency should cooperate with health care advocacy groups, community groups, managed care organizations, physicians, State and local governments, the Health Care Financing Administration, OCR, and other HHS components, to design a data collection instrument that will collect information that is sufficient to carry out the civil rights mandates of the Hill-Burton Act, title VI of the Civil Rights Act of 1964, title IX of the Education Amendments Act of 1972, the nondiscrimination provisions of the block grant statutes, as well as State and local civil rights

⁹⁷ See chap. 4, pp. 146–50.

⁹⁸ See chap. 4, pp. 146–50.

⁹⁹ See chap. 4, pp. 153–55.

laws. The agency should use the HCFA form 1450 as a basis for the new collection instrument, including at a minimum, the data discussed in the Commission's first recommendation under Data Analysis.¹⁰⁰ If these recommendations are followed, eventually there should emerge a comprehensive data collection system that catalogues access, diagnosis, testing, treatment, and outcome on a patient- and physician-specific basis, by race, ethnicity, and gender. Only then will civil rights enforcement agencies, researchers, and policymakers have the information they need to identify and respond to discrimination in the health care industry.

Once a comprehensive database exists, it will benefit OCR and other civil rights enforcement agencies in many ways. First, the agencies, including OCR, should link the database with their complaints tracking systems so that information provided during the preaward stage, as well as information on complaints, compliance reviews, and any findings of discrimination contained in this database, can be cross-referenced to information on funding sources, services provided, and demographic information on patients and beneficiaries of the Nation's health care programs.

Second, civil rights enforcement agencies will have the capacity to plan systematic reviews of *all* recipients of HHS funding. For example, to ensure that each recipient undergoes a compliance review every 3 years, an agency could use the database to identify which recipients are to be reviewed in a particular year. The database should be designed so that information on recipients can be organized by type of facility, amount of funding, etc., so that the information can be sorted in different ways, as needed. The information contained in the database could also be used to conduct research. For example, the data could be used to determine compliance among certain types of facilities, or to determine the types of facilities that treat certain groups.

Third, such information also could be used as a performance measure to determine if the civil rights enforcement agencies themselves are achieving their mission of ensuring nondiscrimination in health care.

OCR's Process of Civil Rights Enforcement: The Case Resolution Manual

Finding: OCR has a *Case Resolution Manual* (CRM), which provides procedural guidance for conducting complaint investigations, compliance reviews, and preaward reviews related to title VI, and for generally implementing nondiscrimination provisions in HHS' block grant programs. However, the CRM is brief and cursory in its procedural guidance on conducting compliance reviews and complaint investigations and does not provide illustrative examples to more clearly identify all elements of the procedural process. Such examples are helpful because they assist investigative staff in comparing fact patterns and evidence gathered in several different cases to illustrate clearly what kinds of information and how much is required to make a case under different theories of discrimination.

In September 1998, DOJ's Coordination and Review Section (CORS) released to civil rights enforcement agencies a far more detailed and comprehensive procedural guidance than the Department of Health and Human Services' Office for Civil Rights CRM. CORS developed this document in response to the many requests from Federal civil rights enforcement agencies to prepare guidance on investigative techniques. It includes sections on applicable legal theories, such as disparate treatment and disparate impact; a description of the evidence required to complete investigations under these theories; methods for analyzing evidence; and detailed sections on settlement agreements, letters of finding, and investigative reports. Compared with the CRM, it is by far the more complete and useful document.¹⁰¹

Recommendation: In general, OCR should ensure dissemination and thorough familiarity with the title VI Investigative Procedures Manual issued by DOJ/CORS in September 1998. In order to ensure guidance specifically addressing procedural issues in the health care and human services context, OCR should use the DOJ/CORS investigative manual to develop its own manual, covering each of the statutes it enforces. This document should be able to "stand alone" as a source for information on procedures on such investigations. It should be an indepth, detailed manual that provides illustrative examples that

¹⁰⁰ See this chap., p. 324.

¹⁰¹ See chap. 4, pp. 155-78.

are sufficiently thorough to provide investigative staff with the kind of comprehensive desk reference that would be an effective tool in facilitating the proper completion of investigative tasks. In addition, it should provide detailed guidance that can facilitate the integration of title VI enforcement into every type of HHS grant program.

OCR should provide the document to staff in a binder with multiple, removable parts separated by tabs. Using this approach, OCR should be able to develop a comprehensive manual while allowing staff to focus only on the sections they find most useful. In particular, OCR should focus its attention on the development of its discussion on evaluating the complaint. It should also focus on providing specialized implementation and enforcement procedures particular to HHS' block grant programs; specifically addressing how OCR uses the disparate treatment and disparate impact theories in fashioning approaches to establishing cases of discrimination in the health care/human services context; and providing title VI enforcement staff and funding recipients with step-by-step instructions for implementing title VI, from the application and preaward process through compliance review and complaint processing, in each type of program for which HHS provides funds.

Finding: OCR's *Case Resolution Manual* instructs civil rights staff on the process for conducting medicare preaward clearance reviews. That process includes collecting certain demographic data concerning the applicant's service area and staff. However, the manual does not indicate how OCR staff should utilize the collected data.¹⁰²

Recommendation: In addition to setting forth the type of data to be collected from medicare applicant facilities and the process for its collection, the *Case Resolution Manual* must instruct staff concerning the purpose for collecting such data from actual and potential providers. For example, the manual should explain that OCR staff should use the demographic data submitted by medicare applicant facilities to determine whether participation rates by racial and ethnic minorities are comparable to rates by nonminorities. It should also instruct staff to consider a prospective recipient's staffing pat-

terns for indications of discrimination in program administration.

Finding: The procedures OCR identifies for conducting compliance reviews in the CRM provide a cursory overview of the efforts the agency will undertake to determine the presence of civil rights violations. The CRM provides almost no detailed procedural guidance on conducting compliance reviews. It merely states that the procedures identified in the CRM for complaint resolution and enforcement should be utilized for compliance reviews, as appropriate. However, given the significant differences between compliance reviews and complaint investigations, this cursory statement appears inadequate. Among the key differences are that: compliance reviews are systemic in nature, whereas complaint investigations generally are far more limited in scope; the kind of information and the means of gathering it may vary significantly between compliance reviews and complaint investigations; and compliance reviews require a carefully planned design before they are begun. Moreover, the CRM's compliance review section does not address any other specific topics or issues on which OCR is focusing or might focus on in the future. Investigative procedure will differ based on which one of these issues is involved. The lack of specific procedural discussion on various issues seems to be another example of OCR failing to achieve the proper balance between streamlining and completeness with the CRM.¹⁰³

Recommendation: OCR should revise the CRM to include a more thorough procedural discussion on compliance reviews. The procedural discussion on postaward compliance reviews should include a discussion on the development and implementation of investigative plans for conducting compliance reviews. OCR should revise the CRM to include separate procedural discussions tailored to various general and specific contexts such as disparate impact cases, racial medical redlining, managed care, medical school admissions, nursing home segregation, staff privileges, access to health care financing programs such as medicaid and medicare, and participation of women and minorities in health care research programs. In addition, OCR should include separate sections on the various issues. This section should explain in detail the ele-

¹⁰² See chap. 4, p. 160.

¹⁰³ See chap. 4, pp. 168-69.

ments needed for developing an investigative plan, including a clear statement of the objective, a thoroughly researched discussion on the subject(s) of the compliance review, and step-by-step instructions on how the compliance review will be conducted.

OCR should develop a revised CRM that contains a detailed discussion for full- and limited-scope compliance reviews along the lines of the one the CRM provides on medicare pregrant clearances. The revised section on full- and limited-scope reviews should address the different procedural requirements for specific issues such as managed care and medical redlining. It should include examples of how prior successful compliance reviews were conducted. These examples should be prepared by the EOS staff that actually conducted them. This section should provide step-by-step instructions, perhaps in the form of a flow chart, on the process for completing a successful compliance review.

Finding: The CRM requires OCR staff to send an information request to complainants whose claim OCR has determined is within its jurisdiction. Some of the language on which the information request is based is somewhat technical and may not be understood fully by the layperson. For example, the potential complainant may not be aware of the "remedies/relief" available to him or her. In addition, the CRM states that OCR will only initiate complaint resolution procedures for those allegations for which "sufficient" information is provided. This is a very subjective term, yet the CRM does not provide any guidance to potential complainants on what constitutes "sufficient" information. Complainants therefore do not know how much information they must provide in order for their allegation to contain "sufficient" information. Moreover, it is OCR EOS staff who are the professional investigators and know exactly what kind of information they need to begin the investigation.¹⁰⁴

Recommendation: OCR must revise its CRM to more clearly define the standards and criteria it is using to determine whether information is "sufficient" or how "remedies" and "relief" are defined in civil rights law to explain to complainants exactly what information they must provide. In addition, OCR should be

working with the complainant either by telephone or in person to gather necessary information rather than placing the burden entirely on the complainant to provide more information.

Finding: The CRM's final section on attempting to resolve the complaint is on monitoring. This is an extremely important aspect, not only of complaint and compliance review resolution, but it is also the most important element in ensuring that compliance is maintained among recipients long after the complaint investigation or compliance review has ended. The CRM, however, gives its section on effective monitoring implementation short shrift. It mentions that "monitoring is critical to ensure that all necessary action is completed." It also states that "whenever appropriate, OCR should keep in touch with the recipient, the complainant and any other pertinent parties" and "monitoring may or may not require an on-site visit." However, the discussion does not provide the degree of emphasis on monitoring activity that it would have if it were more in depth. Statements such as: "whenever appropriate, OCR should keep in touch," and "monitoring may or may not require an on-site visit" seem far too tepid to carry with them the message that OCR is intent on performing vigorous monitoring activities.¹⁰⁵

Recommendation: The CRM discussion on monitoring should go beyond the general statements it makes to offer specific examples of monitoring activities appropriate for various kinds of compliance agreements. For example, OCR has placed a significant amount of emphasis in recent years on the LEP issue. The CRM discussion might address effective means of ensuring that a recipient who has agreed to develop a policy on LEP actually follows through on developing that policy. More importantly, OCR must ensure that such a recipient *actually implements* that policy in a nondiscriminatory manner.

A section in CRM should include requirements for at least two onsite monitoring visits, the development of monitoring reports, and a final evaluation of compliance before closing the case. The final evaluation should signal the closure of the case. However, final evaluations should not occur for at least 1 year after the resolution of the case. This section should formalize staff monitoring procedures both before

¹⁰⁴ See chap. 4, pp. 172-74.

¹⁰⁵ See chap. 4, pp. 175-78.

and after OCR has reached agreement with an HHS or Hill-Burton funding recipient. This section in the manual should place particular emphasis on cases where OCR has met with continued resistance from a recipient in fulfilling its legal obligations. In addition, this section should contain examples of new and innovative monitoring activities conducted in the regional offices. To ensure that quality is not compromised for improvements in efficiency, OCR should provide sufficient staff training on using the manual and continue its training on team-based decisionmaking.

Finding: The CRM addresses negotiation techniques from a broad perspective, in keeping with OCR's intention to make the CRM a more flexible, less prescriptive procedural manual. However, because of the importance OCR attaches to negotiating settlement and corrective action agreements with recipients as a means of resolving cases, it seems that the discussion here might at least contain some illustrative examples for references it makes. Overall, this discussion on securing compliance suffers from the same lack of detail and helpful examples throughout the manual.¹⁰⁶

Recommendation: In revising its *Case Resolution Manual* to provide guidance to investigators, OCR should include specific examples in its discussion on conducting negotiations. For instance, the statements about developing "strategies regarding the roles played by various members, appropriate remedies," etc., might be more useful to investigative staff if the CRM offered examples of how these techniques have been or could be used in various cases. To create the most effective examples, OCR should draw on actual cases as models.

Assurances of Compliance

Finding: Department of Justice coordinating regulations require that, prior to approval of Federal financial assistance, Federal agencies must make a written determination as to whether the applicant is in compliance with title VI. As a basis for this determination, agencies should rely on the submission of an assurance of compliance and a review of the data submitted by the applicant. According to OCR, other documents reviewed for civil rights compliance may include the applicant's nondiscrimination policy,

infectious control policy, section 504 grievance procedure, patients' rights handbook, and age-related policies for compliance with applicable civil rights laws.¹⁰⁷ OCR also informed the Commission that once an institution has established its civil rights compliance through filing an assurance form, that institution's status remains in effect permanently, unless the facility undergoes a change of ownership or other significant organizational or policy/practices change which require the submission of a new assurance form. However, OCR did not list a finding of liability in a civil rights lawsuit as one of the reasons why it would require an institution to undergo a new assurance process.¹⁰⁸

Recommendation: OCR should discontinue the practice of allowing recipients that have established civil rights compliance through the signing of an assurance form to maintain this status permanently. Instead, OCR should require all recipients to resubmit these forms every 5 years. The assurance form should be amended to include questions that would allow OCR to appropriately evaluate the recipients' civil rights record over the preceding 5 years. In addition, recipients that have been found liable in civil rights suits should be made responsible for reestablishing their compliance standing.

Preaward Reviews

Finding: Preaward reviews are extremely valuable because they allow Federal agencies to correct discriminatory practices before recipients are afforded Federal funds. Preaward reviews can also be used to require applicants to take preventive measures to ensure that discrimination will not occur in their programs as a condition of receiving funds. Furthermore, preaward reviews serve as an effective means of targeting State or local continuing program recipients that may need technical assistance or more extensive onsite compliance review. Preaward reviews of such applicants are designed to be more thorough than the collection of assurance forms. They are designed to fully determine recipients' title VI compliance status and to eliminate discriminatory practices before they adversely af-

¹⁰⁷ Perez letter, June 3, 1999, "HHS OCR Headquarters Follow-up Questions," p. 10, item. 20.

¹⁰⁸ See chap. 4, p. 159.

¹⁰⁶ See chap. 4, pp. 176-77.

fect potential and actual assistance program beneficiaries.

As the Commission found in its 1996 title VI enforcement report, HHS lacks a comprehensive preaward review process for all program applicants and recipients receiving HHS funding. Although most of HHS' operating divisions require assurances of nondiscrimination with applications for program funding, the divisions do not perform preaward reviews. OCR's regional and headquarters investigative staff do perform preaward reviews, but only on medicare applicant facilities and providers. As such, HHS disburses an enormous amount of Federal financial assistance without first ensuring that assistance to *all* program applicants and recipients is being allocated in an equitable and nondiscriminatory manner. It appears that outside the medicare context, OCR's current method of simply ensuring that applicants for HHS funding have signed the appropriate form is a very *de minimus* approach to its preaward review activity.

Vigorous title VI enforcement requires more thorough means of ensuring that applicants are complying with nondiscrimination requirements before receiving Federal funds. The limited focus of HHS' preaward review process impedes an effective title VI compliance and enforcement program. Without a preaward review, program beneficiaries may experience discrimination before HHS can identify and address it at the postaward stage.¹⁰⁹

Recommendation: The Commission concurs with the Department of Justice that preaward reviews, both desk audit and on site, are essential to an effective title VI enforcement program and, therefore, OCR should conduct them on all HHS program applicants and recipients. OCR must commence preaward reviews of *all* grant applicants immediately, in addition to securing and evaluating assurances of nondiscrimination. Further, since HHS' title VI regulations require each State to develop methods of administration for State continuing programs, OCR should assess, *prior to granting funds*, States' methods of administration as well as their annual reports or self-assessments on title VI enforcement, for the previous year or period subsequent to the last compliance review.

All preaward reviews should be aimed at identifying discriminatory practices in the delivery of program services based upon evidence, such as unequal participation rates. For example, in HHS research grants, the demographic makeup of the participating students as compared with the demographic makeup of the pool of applicants might indicate barriers to participation, such as overt discrimination or discriminatory criteria in selection practices. Preaward reviews should involve an examination of documents related to recipients' administration of a particular Federal program, including, but not limited to: (1) enforcement and compliance activities, (2) program and participation rates by racial and ethnic minorities, (3) applications or interview material related to program participation, (4) the demographic makeup of the program's affected community or pool of potential participants, (5) rejection rates, and (6) community outreach and public education materials. In addition, OCR should require from all funding applicants annual reports on civil rights activities before awarding funds.

If a preaward review would place too long of a delay in the grant award process, OCR should modify HHS' title VI regulations to include provisions that require all applicants and recipients to report: (1) any formal complaint or other legal action that alleges discrimination, (2) any findings of noncompliance by other Federal agencies that conduct compliance reviews, and (3) records of all discrimination complaints received from beneficiaries as well as their status or findings. These data should cover the period subsequent to the last compliance review or the preceding 5 years for a first-time applicant. Reporting of these data to OCR should be a precondition to receiving funds with a sanction of prohibition, suspension, or termination of funds for failure to report or for providing false information. OCR should especially conduct preaward onsite reviews if this basic preaward desk audit reveals a likelihood of noncompliance with any civil rights law.

Finding: The Commission recognizes that a lengthy preaward process will delay program benefits and, in effect, adversely affect on ultimate beneficiaries. However, it is necessary for OCR to find ways of conducting more vigorous enforcement at the preaward stage that is time and cost efficient, particularly in light of recent

¹⁰⁹ See chap. 4, p. 159.

emphasis on downsizing and restructuring of the Federal Government.¹¹⁰

Recommendation: Due to fiscal constraints, the Commission recommends some alternative strategies for conducting the preaward process for as many applicants and recipients as possible, eliminating reliance on cursory preaward reviews. These strategies should serve only as a secondary alternative to the optimal preaward compliance review process described above.

One means of conducting more thorough preawards of nonmedicare recipients in the absence of more funding may be for OCR to conduct a desk audit review on a specific number of funding recipients. For example, OCR could conduct desk audit compliance reviews of 10 percent of its applicants. By relying on sophisticated software packages to perform statistical analyses that can decrease the time needed to conduct a desk audit from several weeks to a matter of 3 days, OCR investigative staff could conduct these preaward desk audits without sacrificing an inordinate amount of time. The level of enforcement activity OCR conducts at the preaward stage could increase significantly through these or similar means. This alternative should allow agencies to have some type of meaningful preaward review mechanism.

Postaward Compliance Reviews: Planning and Priorities

Finding: OCR does not provide guidance on developing investigative plans for the compliance reviews it recommends or requires under the program priorities in its annual operating plan (AOP). For example, OCR lists managed care and hospital services among the program priorities under which each regional office is required to conduct a compliance review in FY 1998. The AOP states that its objective in requiring each region to conduct at least one compliance review of a managed care program is to increase "the number of managed care plans shown to be in compliance with Title VI, Section 504, and ADA." However, even though OCR lists among its program priorities managed care programs and states that its goal with respect to this program priority is to determine "whether minorities. . . have access to nondiscriminatory services"; nowhere does the guidance discuss the

forms of noncompliance for which OCR is searching or the specific objectives it is seeking to address with regard to race discrimination under title VI. It also does not state the specific means the agency would use to establish a showing of noncompliance; nor does it indicate the remedy OCR would seek to fashion if a violation is uncovered.¹¹¹

Recommendation: In general, HHS' postaward compliance reviews should be designed to accomplish the following: (1) identify program services that could be problematic for participants and beneficiaries of all races and ethnicities, (2) investigate allegations of discriminatory barriers to and disparate treatment in participation, (3) evaluate recipients' public education of program accessibility, and (4) identify recipients needing technical assistance or further onsite investigation. They should also be designed to fit each particular type of HHS funding program, including State-administered programs. The results of a postaward review must be in writing and must include specific findings and recommendations for achieving compliance.

Each regional office should develop an investigative plan for each compliance review that the office plans to undertake. Investigative plans should be completed during the fiscal year prior to conducting the compliance review so that there is ample time to finish the investigative plan before going on site. OCR's AOP guidance should contain a requirement that each regional office develop in depth, individualized investigative plans for conducting their compliance reviews under program priorities.

To accomplish these goals, OCR should develop investigative plans that incorporate the following guidelines. First, the recipient's facility should be investigated to identify potentially discriminatory staffing patterns or other potentially discriminatory employment practices. Second, staff should interview funding recipient officials, community members, program participants or beneficiaries, and counselors or interviewers responsible for assisting participants' and program beneficiaries' involvement. Third, compliance policies and practices should be examined. Fourth, participation rates and application rejection rates should be examined. Fifth, applications for assistance, or other interview

¹¹⁰ See chap. 4, p. 162.

¹¹¹ See chap. 4, pp. 164-66.

materials, should be examined to detect possible barriers to participation, such as discriminatory criteria (either intentional or in effect). Sixth, efforts to educate the public and affected community of programs and activities should be evaluated, especially efforts to provide program information to limited-English-speaking communities. If necessary, several of these procedures involving the examination of documentary material could be accomplished by a thorough desk audit investigation.

Further, the AOP guidance should emphasize the importance of developing and implementing investigative plans specifically designed to attain clearly focused objectives. In turn, the region's AOP should identify the actual objectives of its planned compliance reviews and explain how regional offices should conduct compliance reviews to achieve these objectives. Every investigative plan should include an overall design for how the office will approach the review. This design should contain a statement of a specific objective that clearly defines OCR's purpose in conducting the review. This objective should be more precise than simply asking, "Is there race discrimination?" or "Is there discrimination against people with limited English proficiency?" Instead, the stated objective should be parsed into a more focused, more clearly defined, and more attainable goals. For example, in a compliance review in which race discrimination in managed care organizations will be addressed, a stated objective might include a plan to determine whether or not there are racial disparities with regard to a specific procedure such as organ transplantation or heart surgery. If OCR found such a disparity did exist, it would then have to determine the practices that were causing this specific disparity and whether there were ways to change those practices.

Finding: With respect to the initiative on other health care and social services delivery systems, which supports HHS' Secretarial Initiative on Quality of Health Care, the guidance does not require regions to initiate compliance reviews, although it recommends compliance reviews as one of several activities that a region can perform in meeting its responsibilities under the AOP. However, given that this initiative is specifically focused on continuing inequities based on race in the context of important areas such as health care financing, insurance, and

evolving health care delivery systems, a stronger emphasis on the civil rights enforcement component to OCR's effort would seem entirely appropriate.¹¹²

Recommendation: OCR should place the same emphasis on civil rights enforcement activities, such as onsite compliance reviews, in conducting this initiative that it has for other program priorities. OCR should require regions to initiate compliance reviews for its program priority, "Other Health Care and Social Services Delivery Systems." OCR should target all protected classifications under title VI, title IX, and the Hill-Burton Act. OCR should develop a working group to investigate ways of diverting resources toward such onsite compliance reviews.

Finding: It appears OCR has placed little priority on title IX issues in its planning and priorities for compliance reviews. Although it has developed a program priority for FY 1998 that incorporates title IX along with title VI, OCR regional staff report that they have not done any compliance reviews on title IX. The lack of emphasis on ensuring compliance with title IX mirrors the agency's failure to develop adequate regulatory and policy guidance on this statute. The agency reports that it receives very few complaints on title IX. For example, the manager in Region VI stated that approximately 60 percent of resources go into complaints, but his region has not had any complaints dealing with title IX issues for which HHS conducts enforcement efforts. However, a small number of complaints does not mean that no discrimination is occurring; it may be a reflection of weak efforts on the part of OCR to publicize the law.¹¹³

Recommendation: OCR should redirect some of its resources toward compliance reviews under title IX, so that it can better determine whether discrimination is occurring. In order to do this, OCR should make title IX issues a *separate* program priority. Under this program priority, each region should be required to conduct at least one onsite compliance review a year on one or more issues relating to title IX enforcement. Regional offices should focus on such issues as women's participation in clinical trials and women's access to medical study and practice.

¹¹² See chap. 4, p. 165.

¹¹³ See chap. 4, p. 166.

Full-scope vs. Limited-scope Reviews

Finding: The Department of Justice requires that agencies establish a postaward compliance review process. OCR conducts postaward desk audit, or limited-scope reviews in which it generally narrows the scope of the review to one issue. Such limited-scope reviews can be accomplished more quickly and with fewer resources than onsite compliance reviews. Most of OCR's postaward compliance review activity is done in the form of limited-scope reviews. For example, the Commission observed that in fiscal year 1993, OCR completed only 21 compliance reviews compared to its average of 99 compliance reviews for each of the previous 5 years. This trend has continued in recent years. During fiscal years 1996–98, OCR consistently conducted a significantly larger number of limited-scope reviews than full-scope reviews. For example, in fiscal year 1997, OCR conducted 253 limited-scope reviews but only 33 full-scope reviews. In fiscal year 1998, OCR conducted 253 limited-scope reviews and 61 full-scope reviews.

OCR's emphasis on limited-scope reviews indicates a misappropriation of its resources, because these reviews are not as comprehensive as desk audit reviews that encompass one or more statutes, and nowhere near as comprehensive as onsite reviews addressing at least one statute, and all protected classifications under that statute. Using such an approach, OCR fails to enforce all of the civil rights statutes under its care, and thus, fails to ensure equal access and treatment for all protected classifications under those statutes. In particular, OCR's emphasis on limited-scope reviews focusing on only one issue has meant fewer full-scale, onsite reviews which are necessary to thoroughly assess compliance in many instances.¹¹⁴

Recommendation: OCR should not rely as heavily on limited-scope reviews that focus on only one issue. OCR should have an approach that addresses as broad a range of issues as possible, and covers at least one statute. OCR should shift the focus of its compliance review activity from limited-scope reviews to full-scope, onsite reviews, particularly for those recipients whose desk audit reviews show evidence of non-compliance. Given present staffing levels, OCR should use full-scope, onsite reviews that focus

on one or more statutes, to ensure recipient compliance with title VI, Hill-Burton, title IX, and the nondiscrimination provisions in block grant statutes.

Finding: In identifying requirements for meeting the objectives under each program priority in its AOP guidance, OCR does not distinguish between full-scope and limited-scope reviews. Rather, the AOP only refers generically to "compliance reviews." It appears that whether a review will be limited or full scope depends on the discretion of the regional manager.¹¹⁵

Recommendation: OCR should distinguish between full-scope and limited-scope reviews in its AOP guidance, and should designate certain priorities as requiring a certain minimum number of full-scope reviews conducted per year. OCR should require full-scope reviews in areas relating to title VI health care issues outside the LEP context, such as discrimination on the basis of race under title VI, an area which OCR has not addressed for the most part. In particular OCR should require full-scope reviews of nursing homes, home health care agencies, medical school admissions policies, managed care organizations, and medicare/medicaid providers.

For other priorities, OCR should determine which ones require full-scope reviews based on input from the regional offices, the Secretary, and interested civil rights advocacy groups. OCR should offer each of these entities participation in determining whether a program priority, as well as a recipient that is not part of a program priority, requires a full-scope or a limited-scope review. OCR should develop internal guidelines based on this input and make these guidelines part of its internal policy. All regional offices should be required to use the guidelines to identify subjects for compliance reviews. The guidelines should require regional managers to justify in writing the rationale for conducting limited-scope rather than full-scope reviews, as well as the rationale for choosing to do a full-scope review. OCR headquarters then should determine whether there are areas where a given region is neglecting a particular statute or issue.

OCR should ensure that staff are provided direct access to case files through a personal computer-based case information system. Such a system would enable OCR headquarters to track

¹¹⁴ See chap. 4, pp. 167–68.

¹¹⁵ See chap. 4, p. 167.

all the full-scope and limited-scope compliance reviews, as well as complaints, that each region processes on the system. This computer-based case information system would allow OCR to retrieve all necessary information on each case, including information on the recipients, statutes, issues, and findings. The guidelines should identify specific criteria for OCR staff to use in determining whether it should conduct a full-scope or a limited-scope review. For example, OCR should be able to determine whether a specific recipient has had past compliance problems or a history of complaints filed with OCR. By providing OCR managers, attorneys, and investigators direct access to information on the status of all HHS civil rights cases, the system would allow OCR to more effectively track and process complaints and compliance reviews. More importantly, OCR will have a comprehensive database of all recipients' civil rights status, making access to such information about HHS recipients easily accessible to staff.

Targeting Sites for Compliance Reviews

Finding: OCR targets recipients for compliance reviews based on a list of national priority issues developed by headquarters staff, or if research or other information, such as lawsuits, complaints, or a history of noncompliance, suggests that they may have a compliance problem.¹¹⁶

Recommendation: OCR should review carefully its current methods of site selection to find ways of improving its targeting methods. For example, OCR should expand its selection process for compliance reviews to include more input from individual members of communities in service areas for specific health care facilities. OCR should rely far more heavily on the voices of minority communities, such as neighborhoods and areas that are primarily African American, Latino, or Asian American, as well as women in general, by conducting frequent "town meetings" in various locations around the country. OCR regional staff should host town meetings with advance notice, and times and locations to attract the greatest number of individual community members. OCR should encourage attendees to voice any concerns they may have about the nearest health care facilities in their service area. OCR should make every effort to have

well-known figures in the medical and research communities, such as current and past surgeons general, to speak at these town meetings and to answer attendees' questions. Guest speakers should be encouraged to speak on such subjects as the concepts of standard of care, appropriate care, and quality of care. These meetings will provide OCR with the essential input that will assist staff in selecting where compliance reviews will have the most impact on minority communities and women.

In addition, OCR should broaden the scope of its information gathering in targeting sites by enhancing and expanding its research efforts. OCR relies on such research to some extent in targeting sites for conducting compliance reviews, but more emphasis on research is needed. OCR should assign regional staff on a rotating basis to develop significant research projects to help identify the best targets for review. OCR headquarters should provide specific guidance on available research tools and areas where research is needed. OCR regional offices should assign staff on a rotating basis to the task of developing research reports based on research studies, newspaper articles, and other sources to make recommendations on what issues are relevant and where OCR should conduct compliance reviews. These research efforts should be undertaken as official duties included in the job descriptions for the EOS position. OCR should ensure the most effective and thorough research by providing training on the use of "high-tech" research tools such as the Internet and electronic research databases such as Lexis/Nexis.

When selecting recipients for review, OCR also should rely on complaints filed with the agency in the past 5 years, including those where violations were found, those closed with no violation findings, and those resolved through alternative dispute resolution. To ensure that these complaints can be used for purposes of more effectively conducting site selection, OCR should maintain copious, well-documented electronic files on every complaint case that it addresses.

Systemic Reviews

Finding: OCR states that its pivotal objective in conducting a compliance review is "to address comprehensive systemic issues." However, the extent to which OCR has been able to achieve that objective, at least with regard to

¹¹⁶ See chap. 4, pp. 167–68.

title VI race discrimination, is questionable. For example, despite overwhelming evidence of large-scale racial disparities in access to health care throughout the health care industry, it appears that OCR compliance reviews, rarely systemic in nature, often do not address the significant disparities by race, ethnicity, and sex, that are found in almost every health care context imaginable, such as the managed care industry, nursing homes, home health care, medical school admissions, medical research, and minority staff privileges. Moreover, the CRM itself implies that even when a compliance review indicates a potential violation, OCR will not necessarily investigate. The CRM states “Whenever a compliance review indicates a potential violation, OCR should offer technical assistance to resolve the matter. Alternately, at the discretion of the regional manager, OCR may initiate an investigation to more thoroughly examine the underlying issues or to seek legally binding agreements to effectuate systemic remedies.” With guidance suggesting a reluctance to investigate a potential violation, rather than a firm proactive stance on compliance, OCR already has hindered its ability to ensure compliance. Based on the Commission’s evaluation of OCR enforcement activities, the extent to which OCR thoroughly examines underlying issues to effectuate systemic remedies appears to be quite limited.¹¹⁷

Recommendation: OCR should conduct more systemic title VI compliance reviews addressing race and color discrimination. To accomplish this, OCR should make title VI race and color discrimination a program priority beginning with the upcoming fiscal year. OCR should make the theme of this program priority “Addressing Adverse Racial/Color Discrimination in the Health Care Industry.” This program priority should require that each region, at the present staff level, do as many full-scope compliance reviews a year as resources will allow. In addition, regional offices should each develop a draft of a policy/legislative guidance and send it to OCR headquarters, which will finalize this document.

In addition, OCR should place far more emphasis on conducting more thorough investigations in order to establish compliance violations and effectuate systemic remedies. OCR immedi-

ately should convene a meeting of all regional managers to develop a strategy for conducting, particularly with respect to the managed care industry, the kind of indepth comprehensive reviews needed to uncover systemic compliance violations and effectuate legally binding remedies. At a minimum, this strategy should involve staff training in conducting systemic reviews, a coordinated and organized research plan for targeting sites to review, and the development of quality assurance teams to review the work of investigative staff in conducting reviews and in developing important policy guidance documentation.

To effectuate a comprehensive compliance review system, civil rights staff must be trained to conduct onsite compliance investigations. OCR should conduct the most thorough onsite reviews possible. OCR should focus on how racial/ethnic and gender disparities in access to health care are related to the recipient’s policies and practices by examining the nexus between the disparities and the recipient’s actions. OCR also should ensure that it has medical experts available to assist staff. OCR should focus on the data for specific practices, such as medical treatments and procedures. For example, if OCR staff were to detect a racial disparity in the rate at which diabetic patients were subjected to amputation, its staff must have appropriate medical expertise available in order to develop a compelling analysis showing that discriminatory effect or treatment is occurring.

Overall, OCR should focus on specific objectives rather than unfixed, amorphous goals. OCR should make race and gender discrimination in health care a priority in conducting compliance reviews. The process of using civil rights enforcement to address racial disparities requires OCR to improve and enhance its site selection techniques, develop focused investigative plans, and acquire unlimited access to HHS medical expertise.

OCR’s Overall Compliance Review Process

Finding: One commentator, writing about what he refers to as the “high water mark” of civil rights enforcement in the health care context, the years from 1964 to 1968, notes that this period is instructive of what is required to conduct aggressive enforcement of civil rights compliance. He suggests that in 1999 OCR should

¹¹⁷ See chap. 4, pp. 168–69.

pattern compliance review activities after those conducted in the 1960s.¹¹⁸

Recommendation: OCR should become more creative and aggressive in conducting the compliance review process. OCR should do so by reviewing the civil rights compliance efforts in health care undertaken in the 1960s. OCR regional offices should develop and/or reinforce its contacts with local civil rights organizations. In addition, it should reach out to local physicians and hospital employees who are intimately familiar with the operations of local hospitals to help target problem areas. OCR should hire individuals familiar with civil rights issues in health care, such as attorneys who have litigated in this area, scholars who have written on these issues, and health care advocates, to work as consultants in helping the agency address racial/ethnic and sex discrimination in the health care industry.

Complaint Investigations

Finding: Complaint investigation employs the majority of OCR resources. However, even though more than 60 percent of OCR work is devoted to complaint processing, the inventory of complaints has dramatically risen especially with the increased inflow of complaints since 1988. In response, OCR has recently instituted a “high priority” caseload program concentrating resources on cases most likely to result in findings of discrimination. It is also using alternative dispute resolution techniques and is in the process of revising its *Investigative Procedures Manual* to reflect the “best practices” on case management in the regions and headquarters.¹¹⁹

Recommendation: OCR must initiate more aggressive methods for eliminating its complaint backlog and efficiently processing and resolving its complaint responses, without sacrificing other, equally important, enforcement procedures, such as preaward and postaward compliance reviews of recipients. To do this, OCR should increase proactive enforcement measures, such as preaward desk audit reviews. The focus on proactive measures should prevent funding from reaching organizations that discriminate; it should enable recipients to receive technical assistance and voluntarily eliminate

barriers to equal access and participation in quality health care; and it should require recipient self-assessments as part of grant or contract obligations. Generally, OCR should focus its efforts on evaluating the conduct of funding recipients, especially grant applicants, as a means of preventing complaints from ever arising.

Finding: OCR’s current procedures for complaints intake may have several deficiencies that hinder effective complaint response. First, it appears that OCR finds a large number of complaints meritless and does not proceed with an investigation after intake.

Part of the reason for these problems may be that OCR has not fully implemented a team approach using both attorney and EOS staff to conduct complaints intake. OCR currently does not require regional legal staff to work with investigative staff on every complaint intake procedure. However, attorneys can help clarify allegations, make EOS’ initial assessment efforts more global and more focused, and expedite the overall intake process. Although OCR should use investigative staff to make an initial determination of which category a complaint should be in, OCR must ensure that the categorization of charges is reviewed by supervisors and attorneys after the interview to ensure that the correct category has been assigned. Currently, this is not the procedure in most regions, as several regional attorneys have told the Commission that they generally are not involved in intake procedures.¹²⁰

Recommendation: OCR should fully implement a team approach to conducting intake that would require both regional EOS and legal staff to participate. OCR should rely on the expertise of legal staff as a means of more effectively streamlining its approach to complaint processing. In addition, OCR should seek to compensate for screening out of valid complaints of discrimination that may have occurred before the implementation of this team approach by conducting more compliance reviews, particularly in areas associated with systemic discrimination such as managed care and nursing homes.

The Office of Program Operations should conduct a quality assurance review of all the regional offices to assess the implementation of the complaint prioritization procedures. This review

¹¹⁸ See chap. 4, pp. 169–70.

¹¹⁹ See chap. 4, pp. 178–80.

¹²⁰ See chap. 4, pp. 172–73.

should be based on a comparative sample of offices to assess how well offices are doing with the categorization procedures currently in place. OCR should provide additional training to those offices where OPO determines there is a problem with correct charge categorization. OCR should develop a plan to standardize and systematize a team approach across the regions. This plan should ensure that investigative staff and legal staff work closely in a more structured, less *ad hoc* way than they do currently to ensure proper handling of complaints.

Finding: The CRM states that complainants must provide information requested in conjunction with complaints investigations within 15 calendar days of the date of OCR's letter acknowledging receipt of the complaint. If complainants do not provide all of the requested information within 15 days, the CRM states that "the complaint will be closed and the complainant will be so informed." This 15-day requirement seems an onerous burden to place on the potential complainant both with respect to the brevity of time allotted and the sanction for not complying fully in that time. This very short period of time between the date of the notification letter and outright rejection of the complaint surely must eliminate a great many legitimate complaints that could help OCR to uncover non-compliance both at the individual or small group level and at the systemic level. It also must significantly diminish OCR's chances of being an effective civil rights enforcement agency. Moreover, the sanction of dismissing the complaint if the information is not received in 15 days is unfair and inconsistent with the objectives of ensuring universal compliance with and conducting vigorous enforcement of civil rights laws.¹²¹

Recommendation: OCR must revise its policy to extend the deadline to at least 30 days. In addition, OCR staff should ensure that the complainant is aware that he or she can contact OCR staff at any time during that 30-day period to discuss any questions or concerns about the requested information. The complainant is not in the role of a private plaintiff who must establish her own case based on a legal cause of action. Rather, it is OCR that must address complaints in its capacity as a civil rights enforcement

agency. OCR has the responsibility of investigating complaints to ensure compliance with the statute.

Finding: OCR's charge categorization may be misunderstood by respondents, charging parties, and other individuals outside OCR. Complainants may not understand the prioritization system and whether they can influence the decision process. Moreover, complainants may not know how to frame their complaint so that the important facts are made clear. Similarly, intake personnel may not be able to determine if there are bases for discrimination other than as described by the charging party.¹²²

Recommendation: OCR should develop materials to explain the priority charge handling procedures to groups outside OCR, particularly charging parties. These materials should include user-friendly outreach and education documents that would clearly explain OCR procedures for charge intake and prioritization of complaints. In addition, these documents should thoroughly explain the types of information OCR relies on in reviewing and categorizing complaints. These documents should also provide people planning on filing a complaint with OCR information on what they can expect from the moment they walk in the door or send a written complaint until they have a determination on their case. These materials should be disseminated widely among the public to ensure that as many people as possible have access to specific information on how to file a title VI, Hill-Burton, or other civil rights complaint and how OCR addresses complaints once they have been filed.

Finding: The Commission commends OCR for its effort to resolve complaints through alternative dispute methods. However, this break with traditional investigative procedures may be creating an unintentional erosion of investigative skills. Two similar alternative dispute resolution tools, early complaint resolution (ECR) and predetermination settlements, provide examples of some potential negative consequences. Both of these processes involve negotiating with the recipient and attempting to close the case before making any actual findings of violations.

First, regarding the early complaint resolution process, the CRM is unclear about what OCR's role as facilitator actually entails. It appears from the CRM that OCR does not actively

¹²¹ See chap. 4, pp. 173-74.

¹²² See chap. 4, p. 175.

represent the complainant during negotiations with the recipient. This could create an imbalance of power in favor of the recipient. Second, it appears that with ECR no monitoring is required. If the recipient does not comply with the agreement after negotiations, this could leave the complainant with no other remedy than to file another complaint with OCR. Thus, the complainant would have to start the process anew, as though the first complaint had never been filed.¹²³

Recommendation: OCR should revise its procedural guidance to emphasize the importance of thorough investigations and detailed written findings as well as alternative dispute resolution techniques. OCR should require some form of monitoring for *every* complaint case that is resolved through ECR or predetermination settlement.

In addition, because ensuring system compliance is one of OCR's priorities, the CRM should include case closure protocols that require investigators to do a "compliance review feasibility analysis." The analysis would assess whether the circumstances surrounding the complaint suggest pervasive, institutional discriminatory practices, complex or novel questions of law or fact, or other conditions that could result in a disparate impact on a large number of beneficiaries. If any of these conditions are present, then the case should not be closed, but expanded into a systemic compliance review. The individual whose complaint triggered the review could have the option of settling early or waiting for the outcome of the compliance review.

Because it has focused so little of its attention in these areas, OCR should take particular care in conducting the compliance review feasibility analysis on cases involving race or color discrimination under title VI; and sex discrimination under title IX. In addition, OCR should keep detailed records of any followup activities performed in complaint cases resolved through settlement agreements. These files should be available in electronic format.

Case Closure Documents

Finding: It is important to inform recipients that have been the subject of a complaint investigation or compliance review of OCR's findings.

Therefore, OCR's case closure documents can be the most important written contact between OCR and recipients. The analyses of compliance standards enunciated in them should be thorough and clear. These documents must contain an accurate and complete description of OCR's investigation. Moreover, these letters are important indicators of the quality and efficiency of OCR's investigative process. The depth and detail of the letters themselves reveal the degree of thoroughness of OCR's investigations. A review of these letters reveals that, in general, the letters are not well drafted, particularly with regard to the standards applied in making determinations of compliance and the description of the investigative efforts undertaken.

However, the extent to which letters of finding and other case closure documents are reviewed by regional managers, supervisory EOS staff, and regional attorneys varies from region to region. Several regional civil rights attorneys have indicated that they usually review cases only when there is a finding of a violation or when the issues addressed are particularly difficult, important, or novel. At least one attorney believes that a review by legal staff is necessary because many letters of finding contain "legal discussions," and it is impossible to know the extent to which a legal sufficiency review of a letter of finding is needed until one is done.¹²⁴

Recommendation: Every recipient that has been the subject of a complaint investigation or compliance review should be fully informed of OCR's investigative activities. OCR should create a task force of OCR headquarters and regional staff, including at least 10 civil rights investigators (one from each regional office), two regional attorneys, and two attorneys from headquarters OGC, Civil Rights Division. The goal of this task force should be to develop and implement more stringent quality assurance mechanisms to ensure that letters of finding and other case closure documents are the highest possible quality with regard to the legal standards applied, the description of the facts, OCR's investigative methodology, and the analysis of compliance. OCR should develop standardized procedural guidelines at the headquarters level for the development of letters of finding that are clear, detailed, and comprehensive and provide a

¹²³ See chap. 4, pp. 176-77.

¹²⁴ See chap. 4, p.184.

step-by-step discussion for drafting the letters that explains the purpose of each step and provides examples. OCR should emphasize in these guidelines the discussion of the investigation itself, which should describe exactly how OCR carried out its investigation, including document and statistical analysis, interviews, and onsite observations. In ensuring that the legal discussion and the analysis of compliance are adequate, all letters of finding should be reviewed by a regional attorney and a senior equal opportunity specialist. OCR should conduct new training on writing letters of finding, particularly on developing analyses for findings of discrimination. In addition, OCR should develop a compendium of model letters of findings and corrective action agreements for each of the statutes it enforces, based on selections made by the task force. OCR investigative staff should be able to rely on this compendium for guidance in developing case closure documents.

Questionable Investigative Approach and Methodology Observed in Letters of Finding

Finding: The Commission's review indicates significant problems with OCR's investigative methods. In particular, individual letters show that the evidence on which OCR relies in determining the presence of discrimination often appears incomplete. Generally, the letters suggest an emphasis on statistics with little or no effort to determine differences in the *quality* of care between white and minority patients.¹²⁵

Recommendation: OCR should develop more effective measures for ensuring quality in its compliance investigations. OCR should provide its staff with more thorough investigative training by taking advantage of the DOJ/CORS training module for civil rights enforcement. In addition, OCR should create "issue-area networks" of internal staff at multiple geographic locations who work in one of several key issue areas, including testing and affirmative action programs, medical redlining, and managed care. The networks should help OCR develop internal capacity and consistency throughout regions by building organizational bridges between staff doing the same job in different parts of the country. Networked staff should collaborate on compliance (social science and policy) issues and

medical and legal issues and provide one another on-the-job coaching and other civil rights support. One of the networks' common objectives will be to refine case resolution tools and thereby increase the timeliness, efficiency, and quality of OCR's complaint and comprehensive compliance review process. A facilitator at the headquarters level should be appointed for each health care issue area network to ensure that a proactive, geographically diverse, multidisciplinary group is maintained for the various health care issues.

In addition, OCR should develop and issue model investigative plans for each of its priority issues. OCR also should identify experts or expert teams among staff in headquarters and the regions who should jointly serve as task forces on specific issues. The model plans should apply the legal theories and policies to actual situations and provide a step-by-step operating plan for OCR's regional compliance teams. OCR should incorporate not only factfinding and analysis information into the plans, but also guidance for negotiating corrective actions and developing remedies. OCR should offer the model plans as guides to ensure uniformity among regional enforcement offices, while still permitting the enforcement offices flexibility to adjust to unique situations. As with OCR's policies and investigative guidance, its model plans should be available to the public for the purposes of explaining OCR's rules and its approaches to proving discrimination. OCR should add these model plans to its Internet Web site and electronic filing system to ensure that its collection of resource guidance materials is complete.

Further, OCR should establish an electronic library to assist the staff research by providing convenient online access to current documents related to civil rights and health care issues, such as Federal statutes, OCR regulations, other pertinent regulations, policy documents, case resolution letters, model investigative plans, scientific and scholarly research literature, reports, surveys, and health care initiatives addressing the health status and disparities of minorities and women. OCR's electronic library should be made available to headquarters staff, regional offices, and all HHS operating division staff by the year 2000. HHS should make the electronic library accessible to all interested parties on the Internet by the year 2001.

¹²⁵ See chap. 4, p.184.

Finding: Another problem with OCR's investigative approach is illustrated by OCR's findings in a case involving a claim of race and disability discrimination. In this case, OCR predicated a finding of compliance in part on the notion that, because no other complaints or grievances had been filed, this somehow helped to show that the recipient had not committed a violation and was in compliance. In this case, OCR found that "the complainant and her family were not treated differently than others based upon their race or the disability of her son" in part because "during 1993, no complaints or grievances regarding race and/or disability and staff behavior toward patients or families were filed." OCR's finding that a lack of complaints suggests that there was no differential treatment on the basis of race and therefore no compliance violation is a faulty conceptualization of investigative purpose and technique. The fact that no other complaints were filed should have no bearing on determining whether or not there was differential treatment in this case.¹²⁶

Recommendation: OCR should explain in training materials or investigative guidance that inferring from a lack of complaints that a recipient is in compliance is an example of faulty reasoning: many victims of discrimination may simply not be aware that their access to quality health care is protected by Federal statute. To address this knowledge gap, OCR should conduct enough outreach and education on the statutes it enforces to ensure that beneficiaries of HHS programs are aware enough of their civil rights to recognize discriminatory conduct and file complaints when appropriate. Otherwise, discriminatory program policies and practices that violate title VI will not be redressed. In addition, OCR should evaluate its postaward compliance review process (both onsite and desk audit reviews) to ensure that it is uncovering civil rights violations.

Incorrect Identification of Compliance Standards

Finding: In one complaint investigation, because the complainant had no witnesses to back up her claim that her family had been discriminated against on the basis of race and because the staff involved did not admit to committing

the alleged acts, OCR determined that "the complainant has not met her burden of establishing that these incidents occurred; moreover, that they were related to discrimination."¹²⁷ This illustrates a more serious problem in that it appears from the letter of finding that, in this case, OCR placed the burden on the complainant to establish a case of discrimination, when in fact the burden is on OCR, as an enforcer of title VI, to find discrimination.

It appears, based on the Commission's evaluation, that OCR regional legal staff interact with OCR regional investigative and program staff on a purely *ad hoc* basis. As a result, there is a noticeable detrimental effect on quality evident in the agency's letters of finding, which legal staff do not review in most cases in most regions. A brief review of some of the agency's recent letters of finding indicates the presence of a problem in identifying correct legal standards on which compliance findings are based. For example, in one case involving a complaint against a New York hospital, OCR's analysis determined that the hospital had not engaged in a "clear and consistent pattern necessary" to establish a violation based on disparate impact. Several OCR regional attorneys have noted that the phrase "clear and consistent" should not have been applied as a standard in this case. To use another example, in at least one letter of finding involving an allegation of race discrimination, OCR appears to have applied a standard alleging discriminatory treatment that bore little resemblance to the well-settled standards of proof applicable in such cases.¹²⁸

Recommendation: In the case above, OCR should not have claimed that the complainant and her family were "not treated differently than others" based on such limited evidence. At most, OCR should have claimed that their limited investigation did not reveal evidence that the family was treated differently from others. To avoid incorrect identification of compliance standards in the future, OCR should conduct twice yearly training on developing appropriate discrimination analyses.

¹²⁷ Paul F. Cushing, regional manager, Region III, Office for Civil Rights, U.S. Department of Health and Human Services, letter to Calvin Bland, president and chief executive officer, St. Christopher's Hospital for Children, Philadelphia, PA, undated (re: docket no. 03943048), p. 4.

¹²⁸ See chap. 4, pp. 187-88.

¹²⁶ See chap. 4, pp. 186-87.

Further, OCR should incorporate this training into its *Case Resolution Manual* in a section called “Developing Discrimination Analyses.” This section should be developed by regional attorneys working with senior EOS staff. It should contain examples from letters of finding of analyses that are correct as well as those that are incorrect and explain why. OCR’s Office of Program Operations should conduct a large-scale quality assurance review of all letters of finding and case closure documents. The review team should comprise small working groups of attorneys, managers, and investigators, representing both headquarters and the regions. During the review process, this group should meet for conference calls as frequently as possible, perhaps once every 2 weeks.

This group should prepare a report with specific recommendations designed to determine particular problems and to upgrade the overall quality of letters of finding and other case closure documents. OCR also should invest in training needs assessment. It should seek to achieve a team approach between the attorney and the EOS staff to ensure that legal standards are applied appropriately.

Timeliness of Case Resolution

Finding: Of particular concern are the several instances where OCR has taken an inordinate amount of time to complete complaint investigations involving allegations of failure to provide health care treatment or other services. For example, in one case, OCR received a complaint on July 7, 1993, but did not issue a letter of finding until nearly 4 years later on June 27, 1997. In this case, a doctor filed the complaint alleging that the hospital where he was employed had discriminated against three of his patients on the basis of race by failing to provide outpatient services. Among these allegations, the doctor maintained that one of his patients, a black male, was denied x-rays and another, a black female, was denied a mammogram examination.¹²⁹ These facts help to illustrate one of the more troubling aspects of the egregious delay in completing this investigation. Unlike other civil rights enforcement agencies such as the U.S. Department of Education and the U.S. Equal Employment Opportunity, which address dis-

crimination in education and employment. OCR is responsible for uncovering discrimination that may affect not just life opportunities but something far more profound—the health and physical well-being of many individuals.¹³⁰

Recommendation: Ensuring the earliest possible resolution of complaints alleging denial of access to health treatment and services must become one of OCR’s top priorities. OCR should issue an internal directive stating that all health care related complaints must be investigated, and a letter of finding issued, within 60 days of receipt of a properly framed allegation.

Virtually No Emphasis on Race-based Discrimination under Title VI

Finding: OCR recently has uncovered medical redlining activity indicating potentially large-scale race discrimination under title VI. Yet this discrimination has not yet signaled to OCR, as it should, the need to make medical redlining on the basis of race one of its program priorities. OCR appears reluctant to tackle cases involving systemic adverse effects on racial minorities in managed health care, medicaid, and medicare programs. In particular, OCR appears largely unwilling to develop the nexus between adverse impact and recipient policies and practices needed to establish a title VI violation on the basis of race in the health care context. While OCR is developing a consistent record on LEP, a national origin discrimination issue, the agency has placed almost no emphasis on uncovering and addressing racial discrimination in its enforcement activities. As a result, OCR is neglecting much of its mandate to enforce title VI.¹³¹

Recommendation: OCR should make medical redlining on the basis of race and color one of its program priorities. This would include the development of a policy guidance, a requirement in the AOP that each region conducts at least one compliance review per year addressing this issue, “rollouts” to health care recipients, and other forms of technical assistance and outreach and education. For its compliance reviews OCR should target home health agencies and other health care recipients situated in or near minority areas across the country.

¹²⁹ Rouse letter, June 27, 1997, p. 2.

¹³⁰ See chap. 4, p. 189.

¹³¹ See chap. 4, pp. 190–91.

Lack of Effective Monitoring Techniques

Finding: It appears, based on the Commission's review of OCR letters of finding and other case closure documents that OCR does not conduct effective monitoring activities. For example, case resolution agreements containing agreed-upon provisions to ensure compliance do not indicate that OCR will conduct onsite visits nor do they indicate that OCR staff will prepare monitoring reports. Instead, such agreements indicate that OCR routinely accepts a recipient's assurance that it will change a policy without ever conducting the necessary monitoring efforts to ensure that the recipient *actually has changed its practices*. Case closure documents indicate that OCR routinely accepts the word of recipients in complaint investigations, even when the recipient has implicitly admitted a violation by agreeing to take corrective action.

Although the Commission recognizes the difficulties OCR confronts in finding the resources to conduct effective monitoring on complaint investigations resolved through resolution agreements, certain followup activities not addressed in these cases are so crucial to the monitoring process that without them OCR cannot know with any certainty that its efforts to ensure compliance have been successful. These include onsite visits, especially those which are unannounced, as well as monitoring reports. Onsite visits in particular provide a highly effective means for OCR to know precisely the extent to which a recipient is complying with the terms of a resolution agreement.¹³²

Recommendation: OCR must conduct onsite monitoring of all cases resulting in findings of noncompliance and all cases ending in a resolution in which a recipient agrees to undertake corrective action of any kind. At a minimum, it seems necessary for OCR to conduct some form of onsite monitoring activity for all recipients that have been subjected to a compliance review or complaint investigation. OCR should use testers in its monitoring activities to ensure that recipients are actually implementing the terms of their compliance agreements. For example, in the LEP context, OCR should use testers to ensure that recipients that claim they will develop an LEP policy are actually providing interpreters to all persons with LEP.

Finding: In a case resolution letter accompanying a recent settlement agreement with a home health agency, OCR does not state explicitly that the home health care agency's policy constituted a violation of title VI. Rather, it states only that the agency's "adherence to the terms of the Resolution Agreement will ensure its future compliance with title VI and the HHS implementing regulations." With this statement OCR is stating implicitly that the policy likely would have violated title VI. OCR did not develop actual findings or an argument to support them because the agency and OCR were able to come to a resolution agreement before such action was needed.

Recommendation: OCR should keep detailed records of investigations where it ended its investigation because an alternative dispute resolution had been achieved. It is particularly important in cases where EOS staff believe there is strong evidence to indicate a compliance violation, with potentially systemic implications, has occurred. In addition, it would be helpful if OCR were to keep a database record or a special file for such cases. Each case record could include the type of potential violation, an application of the essential facts to the appropriate legal standards, and the disposition of the complaint investigation at the time the resolution agreement was reached. This would increase efficiency and consistency in the handling of future cases, as well as facilitate a more comprehensive, issue-specific analysis of OCR's caseload.

Availability of Medical Expertise

Finding: OCR relies on medical and scientific research expertise provided by other HHS agencies. However, the availability of these medical experts to OCR is limited by their job responsibilities to their own agency, which take priority over any assistance OCR may need. HHS currently does not seek to ensure that OCR has medical expertise available when needed. OCR has no formal mechanisms such as memoranda of understanding or procedural guidelines to invoke assistance from personnel in these agencies when it is needed. As a result, OCR may not be able to avail itself of the expertise of HHS physicians or researchers because they are working on another project. The inability to routinely get quality medical advice and expertise

¹³² See chap. 4, pp. 191-93.

has impeded OCR's ability to uncover and prove violations of title VI and other statutes.¹³³

Recommendation: HHS should address immediately OCR's difficulties in accessing the medical expertise of HHS operating division staff. HHS should ensure that civil rights enforcement is among the highest priorities at the agency, in part by providing OCR with medical expertise on a permanent basis. OCR should enter into memoranda of understanding or other formal agreements to invoke assistance from personnel in other key HHS operating divisions as necessary. Procedural guidelines implementing these agreements should ensure that medical expertise is available to OCR whenever it is needed by establishing a rotating basis for designating medical doctors and researchers to work with OCR on pending cases. The operating division should be required to provide such assistance within 24 hours after a request is made. These agreements should clarify that whatever expertise is needed by OCR will be considered a top priority by the operating division. Should it ever be required, OCR should consistently have available, on a contractual basis, outside medical experts to lend their opinions as cases are being developed.

In addition, OCR should develop a more consistent working relationship with operating divisions such as NIH, drawing on the medical and research expertise resources available through those offices to assist in OCR's compliance review and complaint investigation activities. The expertise of medical and research doctors and scientists should be used in the development and implementation of all aspects of the civil rights enforcement process, including development of procedures, standards, and criteria for evaluating the presence of discriminatory practices, remedies, and training materials in the health care context. For example, OCR should work with medical experts to select a set of medical references that will serve as the standard for OCR staff to use in determining discriminatory practices. Further, OCR should incorporate into memoranda of understanding with other operating divisions an ongoing training program. For example, operating division medical and research experts, on an annual or semi-annual basis, could train OCR headquarters and regional

staff on specific practices and standards and brief them on any issues or debates that may have title VI, title IX, or other statutory implications in the medical or research fields.

OCR also should work with the operating divisions to gain electronic access to other resources, such as the MEDLINE library. As part of their memoranda of understanding with OCR, operating divisions should keep OCR informed of the various programs, projects, or research efforts undertaken by or funded through the program offices that may provide useful information to OCR's civil rights enforcement efforts. As operating divisions approve project grants or undertake research projects, OCR will have knowledge of possible sources that can assist in the development of civil rights policy, technical assistance documents, and civil rights medical/research materials on different health issues. For example, if an operating division has done a long-term study of racial disparities in the managed care industry, OCR should use the study to evaluate the need to conduct compliance reviews; to target site selection for compliance reviews; and to develop outreach, education, and technical assistance plans.

Availability of Data

Finding: The Commission's evaluation of OCR's enforcement activities indicates that the agency does not always make effective use of statistical evidence in establishing cases of discrimination under title VI. A finding of a title VI violation requires proof that the recipient engaged in a policy or practice that resulted in discrimination on the basis of race, color, or national origin, whether the recipient intended to practice such discrimination, or whether the practice was neutral but nonetheless caused an adverse impact. Therefore, to establish that the cause of a racial disparity in health care service delivery is a violation of title VI, an OCR investigation must determine the practice that created the statistical disparity. However, the Commission's evaluation of OCR's data analysis activities indicates that the agency is severely hindered in its access to and ability to analyze data to make compliance determinations.¹³⁴

Recommendation: OCR should develop a policy, investigative, and procedural guidance on

¹³³ See chap. 4, pp. 195–96.

¹³⁴ See chap. 4, pp. 196–97.

the need for and uses of data analysis in conducting its compliance reviews and complaint investigations. These guidances should be comprehensive, detailed, and provide illustrative examples. OCR should rely on the informal assistance of private civil rights advocates and State and local agencies to make these guidance materials as complete and comprehensive as possible. To the extent that OCR must convince HHS that it needs availability of more data, these guidance materials should be disseminated throughout HHS and its operating divisions. OCR should obtain the support of the Secretary to ensure that data collection and analysis in civil rights matters is a mandatory requirement. Finally, OCR should work with the Health Care Financing Administration and State and local recipients to ensure that OCR has sufficient data available on each of the following:

- The manner in which services are provided by the program.
- The race, color, and national origin of the population eligible to be served.
- The location of existing or proposed facilities and information on whether the location could have the (unintended) effect of denying access to any person on the basis of race, ethnicity, or gender.
- Racial/ethnic and gender composition of program participants.
- Diagnosis and treatment provided to patients (by race, ethnicity, and gender).
- Racial/ethnic and gender composition of applicant's/recipient's staff.
- Data on the use of bilingual employees to work with program participants and other beneficiaries who have limited English proficiency.
- Lawsuits filed against the applicant/recipient alleging discrimination.
- Descriptions of any applications for assistance pending at other Federal agencies.
- Descriptions of any civil rights compliance reviews conducted in the prior 5 years.
- Information on whether the applicant/recipient has been found in noncompliance with civil rights laws.

Focus on Objectives Identified in Research Literature in Developing Investigative Plans

Finding: OCR lacks detailed, thorough, well-researched investigative plans focusing on a particular issue. However, there is a wealth of research available to OCR that, if used properly, could form the basis of specifically focused, far more efficient and comprehensive compliance reviews. For example, a study published in the *Journal of American Medical Association* showed that black people, women, and the poor are less likely to receive kidney transplants than men, white people and the affluent. This article was disseminated to regional staff as an attachment to a weekly information report from headquarters. It provides a very specific issue to target in developing an investigative plan for a compliance review. Identifying a disparity based on race or sex in kidney transplantation within a recipient facility provides a specific, narrowly focused objective. Determining the extent to which the disparity is caused by factors that can be addressed in a negotiated agreement between OCR and the facility, or through technical assistance, or some other form of action also is a reasonable goal.

Uncovering subtle forms of race or sex discrimination in the health care system presents significant obstacles that have been alluded to in the discussion above. Even with adequate statistical evidence, it is very difficult to establish a nexus between a particular practice and statistical evidence of health care access and outcomes. However, with specific, clearly identified objectives, OCR is much better prepared to make this connection and to determine whether a practice constitutes a violation of title VI or any of the other statutes OCR enforces.¹³⁵

Recommendation: OCR should make the maximum possible use of research literature, not just by reviewing it, but by using it to focus its investigative plans for compliance reviews. OCR should include a component in its procedural guidance on the use of scientific research studies as a means of identifying specific objectives in conducting efficient and comprehensive compliance reviews. For example, each time OCR designs a compliance review, one or more objectives deriving from studies showing racial disparities with regard to specific procedures

¹³⁵ See chap. 4, pp. 197–98.

should be identified, if possible. Then, OCR investigative staff should incorporate each research finding in the investigative plan as a specific objective of the compliance review, along with potential means of proving its presence such as statistical analysis and interviews with recipient staff. OCR should then identify in the investigative plan potential remedies to address the problem once it is uncovered.

Focus on Medical Practitioners and Administrators in Investigative Plans

Finding: Research literature also may help OCR investigative staff to conceptualize compliance problems. For example, a recent research study illustrates the difficulties confronting OCR in developing effective investigative plans while at the same time providing a useful model for defining objectives clearly and manipulating data to establish the all-important connection between evidence and recipient policies and practices. In an article appearing in the *New England Journal of Medicine* in February 1999, researchers published the results of a study that showed doctors are far less likely to recommend rigorous and more sophisticated cardiac tests for black people and women than for white men with identical complaints of chest pains. The study is singularly important. It is the first large-scale study to focus exclusively on treatment decisions made by doctors instead of merely documenting the already well-known disparities in health care status and outcomes.

The authors of the study could not draw any inferences of overt racism or sex bias from their findings. They suggested instead that the problem may be the result of “subconscious perceptions rather than deliberate actions.” If, as this study has done, OCR could shift its focus to include not only evidence of disparities but also an emphasis on eradicating bias among medical practitioners and administrators themselves, it may be better able to identify policies and practices that need to be changed, as well as to develop creative solutions to address the “subconscious perceptions” that appear to be a factor in creating the disparities in health care that exist across racial and gender lines.¹³⁶

Recommendation: OCR should develop investigative plans that include a strong focus on

interviewing and interacting with medical professionals among health care funding recipients, including doctors, nurses, and administrators, in order to gain a more complete, comprehensive perspective on the subjects of its compliance reviews. OCR should make outreach and education programs specifically geared toward medical professionals a key component in all compliance reviews it conducts. This outreach and education component should emphasize the issues related to racial disparities in health care and should include diversity training.

Potential Disincentives to Finding Violations

Finding: Two OCR regional attorneys have indicated that they believe one possible barrier to finding violations is that there are “built-in” disincentives to find violations in title VI race discrimination cases. A third regional attorney stated that he believes OCR places a great deal of emphasis on numbers. He stated that there is a quota system, established at OCR headquarters, that dictates the number of cases to be closed. He also stated that, as a result, complex cases on which OCR could and should spend much time, are closed. This attorney recommended that OCR create a weighted point system to allow regional investigative staff more time closing complex cases.

The presence of a quota or “quota like” system may help to explain why there are so few cause findings in cases involving investigations into race discrimination under title VI since this appears to be a very difficult area in which to establish the presence of discrimination. Having to complete a specific number of complaints within a given period may play a role in how thoroughly individual EOS staff members conduct their investigations. Based on the observations presented above, together with the dearth of noncompliance findings in OCR’s title VI race discrimination cases, it appears that maintaining a balance between meeting targets dates and conducting thorough investigations may require a significant amount of compromise.¹³⁷

Recommendation: OCR should deemphasize the potential for creating “quota systems.” Performance measures should be based on the quality of investigations and comprehensive compliance reviews rather than the speed with

¹³⁶ See chap. 4, pp. 197–98.

¹³⁷ See chap. 4, pp. 198–99.

which a case is closed. For example, OCR should base performance reviews on the thoroughness of the investigative plan, peer reviews on effectiveness of interviewing, and onsite investigative technique. In addition, OCR should develop a system in which EOS investigative staff are given more time to finish complex cases, particularly compliance reviews in the managed care industry. OCR should work with regional attorneys, regional managers, and headquarters staff to develop procedural guidance that adjusts the performance measures imposed on EOS staff for complex cases.

Litigation

Finding: OCR's position would be far stronger with support from case precedent, either administrative or judicial. The continuing prevalence of racial disparities in the Nation's health care system, and the failure of government initiatives and advocacy groups to reduce these disparities, indicates the need for a strategy to more vigorously enforce civil rights laws such as title VI. Several OCR regional and private litigators who have worked on title VI cases in the health care context have agreed that developing means of setting positive case precedent is a goal toward which OCR should be working. OCR must take a more broad-based, proactive approach in its efforts to set precedents that strengthen title VI as a civil rights enforcement mechanism. In particular, OCR should target not just issues where there have been complaints, but contemporary issues publicized in news and scholarly articles, where there continues to be a wealth of new information about racial disparities. These disparities may result from violations of Federal civil rights statutes, and OCR is the only HHS agency that can undertake civil rights compliance reviews to determine the presence of illegal discrimination.¹³⁸

Recommendation: OCR should pursue a strategy of seeking cases to set precedent for stronger compliance standards under title VI. OCR should work with civil rights advocacy groups to find cases with the potential for establishing legal precedent that can reinvigorate title IV as a vehicle for combating discrimination in the health care industry. OCR should work

closely with major civil rights advocacy organizations such as the NAACP Legal Defense Fund (LDF) and the American Civil Liberties Union (ACLU) to develop litigation that could set important case precedent and provide stronger remedies. Working with such advocacy groups, OCR should develop an action plan with a specific agenda. This plan would include convening informal meetings, perhaps by conference call, to discuss cases that may have the potential to set positive precedent. In particular, OCR should focus its efforts on the managed care industry. OCR should work with the LDF, ACLU, and other major civil rights organizations to identify and develop potential cases of discrimination against medicare and medicaid providers that would set important case precedent under title VI.

Civil Rights Review Team Report

Finding: In September 1993, HHS issued a report based on findings and recommendations made by an interagency review team that evaluated all of OCR's enforcement operations. The report made many findings and recommendations, although the agency has not followed up on the report to ensure that its recommendations are being implemented.¹³⁹

Recommendation: HHS should reconvene its review team to revisit recommendations made in 1993. The new task force should be composed of staff from several agency elements, including operating divisions such as NIH and HCFA and staff divisions such as the Public Health and Science Office and OCR. The team should include civil rights and equal opportunity professionals, as well as medical experts. It should conduct a thorough examination of civil rights enforcement activities in OCR. The task force should issue a new report and continue to issue followup reports on a biannual or triennial basis.

Monitoring Recipients of Block Grant Funds

Finding: In the context of HHS-funded, State-operated block grant programs, States are authorized to determine programmatic needs and the appropriate mix of services, set priorities, allocate funds, and establish oversight mechanisms. In addition, Federal block grant provisions authorize States to audit their own programs. Each State agency must annually

¹³⁸ See chap. 4, pp. 204-05.

¹³⁹ See chap. 2, p. 30.

audit its expenditures from payments received under its block grant program and submit completed audits to the HHS Secretary. Moreover, States are required to assume the same civil rights responsibilities over their subrecipients that Federal agencies have over recipient State agencies.

There are few consistent mechanisms for HHS to ensure that States sufficiently oversee compliance with title VI. OCR does not evaluate States' and subrecipients' compliance responsibilities on a regular basis. Although, in effect, State agencies that participate in HHS block grant programs are responsible for title VI implementation and enforcement in the federally financed programs they administer, Federal funding agencies, such as HHS, remain ultimately accountable for ensuring nondiscrimination in State-administered programs.¹⁴⁰

Recommendation: OCR must establish a mechanism to monitor States' civil rights compliance to ensure that States are maintaining sufficient records on their subrecipients' progress in delivering health care services that address the programmatic elements stipulated in a project grant or loan proposal. Further, OCR must monitor States and their subrecipients' procedures and efforts to comply with civil rights statutes and other nondiscrimination provisions, and the distribution of Federal funds from the State primary recipients to the local providers of care.

Developing and Issuing Block Grant Regulations and Guidelines

Finding: As the Commission reported in its 1996 title VI report, HHS has not adopted and implemented title VI regulations designed specifically for ensuring title VI compliance in block grant programs. Although title VI regulations specify that the recipients of HHS funds include States; political subdivisions of States; public or private agencies, institutions, and organizations; and other entities, the regulations do not have distinct provisions for these recipients if they participate in block grant versus categorical grant or other State programs.¹⁴¹

In addition, HHS has not adopted comprehensive policies designed specifically for ensuring title VI compliance in block grant pro-

grams.¹⁴² However, in January 1999, the Acting Assistant Attorney General, Civil Rights Division, U.S. Department of Justice, issued a policy guidance document to executive agency civil rights directors on the enforcement of title VI and related statutes in the context of block grant programs. In this document, DOJ declared that civil rights statutes such as title VI, title IX, section 504, and the Age Discrimination Act apply to State programs, unless Congress intended otherwise. The document also highlighted various title VI coordination regulations. Overall, the document's recommendations relate to how to ensure nondiscrimination in block grant programs.¹⁴³

Recommendation: HHS should revise its title VI regulations to address block grant programs. The regulations should describe that States are responsible for ensuring compliance with civil rights statutes among their subrecipients, and should provide explicit guidelines for conducting specific types of reviews and providing reports of compliance to OCR. In addition, the regulations should specify the types of data to be collected by States in order to determine civil rights compliance.

OCR headquarters should develop and issue guidelines based on DOJ's 1999 policy guidance document on the enforcement of title VI and other civil rights statutes in the context of block grant programs. HHS' guidelines should be written so that they are directly and explicitly applicable to different health care programs and settings, including managed care environments. The guidelines should provide explicit instructions for conducting compliance reviews and collecting data from States and their subrecipients.

OCR headquarters should disseminate these block grant guidelines to all regional offices, in order to have uniform civil rights implementation, oversight/monitoring, and enforcement across all State-administered, HHS-funded block grant programs, regardless of the region in which the programs' services are delivered. OCR regional managers, in turn, should distribute the HHS block grant guidelines to the State officials in their respective regions who are charged with administering block grant programs. OCR should also provide technical assistance to the State agencies so that they understand and are

¹⁴⁰ See chap. 4, pp. 205–15.

¹⁴¹ See chap. 4, pp. 206–15.

¹⁴² See chap. 4, pp. 207–13.

¹⁴³ See chap. 3, pp. 65–66.

able to implement the recommendations within their block grant programs. OCR should stress that the block grant guidelines were developed to assist State recipients in delivering health care services in a nondiscriminatory manner.

A Uniform Procedures Manual

Finding: Some regional offices have tried to ensure that State recipients understand their responsibilities to comply with the nondiscrimination provisions of the 1981 Omnibus Budget Reconciliation Act (OBRA) and administer health care programs in a nondiscriminatory manner. Headquarters OCR, on the other hand, has not developed a uniform procedures manual. However, administrators of various State health care agencies indicated to the Commission that they are in need of a thorough and clear understanding of civil rights statutes enforced by HHS.¹⁴⁴

Recommendation: Because of the inconsistencies across regions regarding the delegation of civil rights compliance, implementation, monitoring, and oversight enforcement responsibilities to States, OCR headquarters should develop and enforce formal written procedures that assist States in conducting complaint investigations and compliance reviews of their subrecipients' health care programs. This document should be directive and detailed, similar to headquarters OCR's 1993 *Investigative Procedures Manual*. Yet it also should allow State agencies to have flexibility and room to use their judgment, as reflected by the more recent 1996 *Case Resolution Manual*.

OCR should follow up its distribution of this procedures manual with mandatory training, including technical assistance, for block grant program administrators in States' health care agencies. This training should help State administrators become familiar with strategies to prevent violations of civil rights statutes and the nondiscrimination provisions of block grant statutes, and with strategies to remedy violations through negotiations and compliance with presettlement agreements, in order to avoid litigation.

State Governors and Block Grant Programs

Finding: Currently, State Governors are not involved in the daily operations of State-

administered, HHS-funded block grant programs. Typically, they are informed about the operations of an HHS-funded block grant program only if a complaint has been filed, if OCR has uncovered a potential civil rights violation during a compliance review, or if OCR is handling a sensitive or controversial matter within the context of a block grant program. However, OCR staff indicated that there have been few instances of noncompliance in which Governors became involved.¹⁴⁵

Recommendation: Governors should be informed about the procedures for block grant programs. OCR should issue guidelines to Governors in order to educate them on civil rights statutes, beneficiaries' rights, and obligations of their respective States' block grant programs. This training should assist Governors' offices in effectively communicating with officials of State block grant programs, and keep them abreast of States' civil rights implementation and enforcement responsibilities. OCR should also ensure effective communication between Governors and administrators of State health care agencies administering block grant programs.

Methods of Administration

Finding: HHS/OCR headquarters currently does not assist State agencies in developing their methods of administration (MOA) or in reviewing and monitoring of MOAs. Similarly, OCR headquarters does not regularly review or direct regional offices to review their respective State recipients' MOA. Consequently, HHS regions vary in their performance with respect to addressing MOAs. OCR has failed to establish a systematic oversight and monitoring program to evaluate the title VI compliance strategies and performance of State and local agencies as they develop and implement their MOAs. However, such assurances are particularly important when the State is responsible for compliance activities, such as preaward reviews, investigating complaints, reviewing and evaluating subrecipients' self-assessments, and conducting compliance reviews.¹⁴⁶

Recommendation: HHS' State recipients should submit MOAs demonstrating how they intend to ensure their own and enforce subre-

¹⁴⁴ See chap. 4, p. 211.

¹⁴⁵ See chap. 4, pp. 207-08.

¹⁴⁶ See chap. 4, pp. 209-12.

ipient compliance with title VI. As the Commission has recommended in several previous reports, MOAs should include, but not necessarily be limited to, the following:

- A mandate that all States have a full-time title VI civil rights coordinator that reports directly to the Governor.
- A specific public outreach and education plan for notifying subrecipients of title VI compliance requirements.
- Training for State and local program staff, subrecipients, and beneficiaries on HHS' nondiscrimination policies and procedures.
- Procedures for processing complaints, notifying the funding agency, and informing beneficiaries of their rights.
- A program assessing and reporting periodically on the status of title VI compliance that involves more than merely a checklist of activities and assurances.
- Detailed plans for bringing discriminatory programs into compliance.
- Responsibilities of the State agency's civil rights coordinator to serve as liaison between the State agency and OCR, as well as liaison between the State agency and community-based organizations representing minorities and women.
- Proactive steps to overcome the effects of prior discrimination against program participants on the basis of race, color, national origin, or disability.
- The State's written nondiscrimination policies and continued notification of these policies to all beneficiaries, program participants, and the general public.

There are additional elements that HHS State recipients, in each OCR region, should include in their MOAs to ensure that all federally funded health care programs are administered in a nondiscriminatory manner and comply with Federal civil rights requirements. For example, at least on a biennial basis OCR regional offices should review State agencies' MOAs to ensure that they contain the aforementioned elements. Similarly, OCR should stipulate that a State revise and resubmit its MOA if agency officials change or if a State reorganizes such that the State and its programs are no longer compatible with the contents of its MOA. In addition, if a

State creates new programs or expands upon existing programs, then OCR should require that States submit updated MOAs for review. Furthermore, each regional office should initiate the necessary compliance actions when agencies do not respond to the request to submit their MOAs.

In addition, each OCR regional office should regularly conduct onsite compliance reviews of State agencies, to evaluate how States are applying their MOAs, particularly with respect to title VI. Such a review can serve as a basis for potential future actions to bring the State agency into compliance with title VI and any other civil rights statute that is addressed in the State recipient's MOA.

Finding: Various OCR regional offices have expressed difficulty in identifying the particular sources of the funds allocated to State agencies and other recipient, since many recipients tend to participate in several HHS programs and receive their allocations as one lump sum rather than in distinct appropriations from each program. This deficiency can hinder OCR's assessment of State agencies' efforts to track and oversee the distribution of funds to subrecipients. The inability to accurately track funds makes it difficult to assess the number of complaints that arise specifically in the context of a particular health care block grant program.¹⁴⁷

Recommendation: HHS should develop a database system that will enable HHS agencies, including OCR, to identify the source of funding for a particular program. OCR should use this system to assess compliance and identify complaints in the context of any specific block grant program. OCR should improve its accuracy in assessing how effectively State agencies track the distribution of funds to subrecipients. Specifically, OCR should develop a database containing information on all HHS funding recipients and the HHS agency or program that provided the funding. This database should be linked to other information, such as complaints received, outcomes of compliance reviews and investigations, and technical assistance provided. In addition, demographic and patient data related to the facilities should be included in this database.

¹⁴⁷ See chap. 4, pp. 209–15.

Assessment of OCR's Technical Assistance, Outreach, and Education Efforts

Finding: As the Commission found in its 1996 report on title VI enforcement, OCR does not regularly conduct community outreach or public education related to title VI. As such, actual and potential applicants and recipients may lack sufficient knowledge of title VI's compliance requirements to effectuate full compliance. Similarly, beneficiaries and participants, and the affected community, may lack sufficient knowledge about title VI's requirements to initiate complaints or otherwise pursue and protect their rights under title VI.¹⁴⁸

Recommendation: Regarding community outreach, OCR must regularly solicit comments and suggestions from affected communities and funding recipients on its title VI enforcement efforts. It also should solicit information on affected communities' civil rights concerns, regarding protection of title VI rights, and funding recipients' compliance concerns, about potential title VI violations and OCR's compliance expectations. Regarding public education, OCR must regularly inform potential and actual participants, beneficiaries, and affected communities concerning the extent of their rights and how to pursue and protect their rights, including procedures for filing complaints. OCR also should ensure that recipients educate the public on program accessibility. Regarding technical assistance, OCR should regularly train its staff and recipients' staff on the methods for achieving enforcement. It should provide step-by-step instruction on conducting procedures such as compliance reviews. It also should inform staffs within OCR's regional offices, the operating divisions, and State and local agencies about new and developing civil rights issues, especially changing case law, statutes, regulations, and policies, affecting title VI enforcement in HHS grant programs.

OCR should create within its headquarters operation an Office of Outreach and Education. It should be a central goal of OCR's newly created Office of Outreach and Education to develop ongoing interactions with community groups and individuals in facility service areas and to learn the needs of different communities, both urban and rural, across the country. Staff

activities should include as many onsite visits as possible to communities across the country. These visits should allow OCR staff members to interact with patients and staff of facilities, local health care advocacy groups, and other stakeholders. These visits should be designed to allow staff members to travel to as many communities as possible to deliver information. One method would be to conduct "marathon" visits, requiring extended periods of travel to several locations. A central goal of these visits would be ensuring that HHS funding recipients along with public libraries, post offices, and other public buildings have visible pamphlets and posters on OCR's civil rights enforcement efforts. OCR should ensure that all recipients, particularly those in service areas with large populations of non-English-speaking individuals, display materials in applicable languages.

Finding: OCR attributes the limited amount of technical assistance and outreach to the minimal amount of funding allocated for such activities. However, budget constraints appear to have affected outreach on title VI and Hill-Burton more than for other statutes. Within the past 4 years, OCR has prepared updated and detailed information on section 504, as well as offer written guidance on LEP, welfare reform, managed care, and certain departmental initiatives. But written technical assistance materials on title VI and Hill-Burton have been limited. During the past 4 years, the regional offices primarily have conducted technical assistance, education, and outreach programs in certain civil rights areas and for HHS programs in social service areas rather than in health care.¹⁴⁹

Recommendation: OCR should assess whether the benefits of allocating more of its resources to outreach and education outweigh the sacrifice of funds in other areas. By providing increased funding and staff for technical assistance and community outreach and education, HHS could increase the number of valid title VI complaints, while reducing the number of faulty complaints. In addition, by focusing more resources on title VI, title IX, and Hill-Burton technical assistance and education activities, OCR will be more effective in securing voluntary compliance with civil rights laws and enhancing

¹⁴⁸ See chap. 4, pp. 216-26.

¹⁴⁹ See chap. 4, pp. 217-18.

public knowledge about OCR's responsibilities in safeguarding their rights.

Finding: Technical assistance, education, and outreach have a significant effect on the success of OCR's compliance and enforcement activities. Through these activities, OCR can inform applicants, recipients, participants, beneficiaries, communities, and advocacy groups of its programs on civil rights protections. These technical assistance and education efforts, if executed properly, can ensure awareness and compliance, and encourage civil rights support. Although OCR headquarters recognizes the importance of technical assistance, outreach, and education activities in its operations, during the past 4 years, it has had little involvement in these activities, provided little guidance to regional offices that conduct such activities and programs, assigned few staff to coordinate and monitor these programs, and not required its staff to perform a specified number or type of technical assistance or outreach activity. OCR is providing these activities on an ad hoc basis, addressing a limited number of issues, and implementing these activities without formal standards or guidelines. In the Commission's assessment, these activities are a low priority in OCR. Moreover, OCR's technical assistance, outreach, and education for title VI race/color discrimination, title IX, Hill-Burton, and nondiscrimination provisions in block grant programs are deficient. This is due in large part to OCR's failure to develop an outreach and education program targeted to minority communities, both urban and rural, that would ensure community members have sufficient information and guidance on their rights under these laws and on activities, such as compliance reviews and complaint investigations that OCR undertakes.

Recommendation: OCR needs to develop formal guidelines for conducting its technical assistance activities. These guidelines should be developed and distributed in the form of a guidance memorandum to OCR regional staff. OCR should ensure that this memorandum is disseminated widely among its recipients and potential beneficiaries. The guidance documents should require each regional office to develop an internal outreach and education plan on an annual basis. The guidance should require each region to address the following in its plan: outreach to minority communities in both inner-city

and rural areas; outreach and education for medical schools to establish diversity training programs for medical students; and technical assistance efforts to provide each operating division and State recipient with appropriate civil rights training. Further, OCR should include in the guidance detailed examples of model plans. These model plans should be developed by an advisory committee composed of staff from headquarters and at least one representative from each regional office. Model plans should include as many innovative ideas as possible for reaching underserved communities and entities such as State recipients, health care providers, medical schools, and HHS operating divisions. For example, model plans might include suggestions for the development of periodical newsletters to recipients, participants, and beneficiaries on departmental initiatives and other information relating to civil rights enforcement; ideas for more efficient technical assistance, outreach, and education efforts; and the development of a mechanism such as a survey to determine the effectiveness of technical assistance. Finally, the guidance should require each OCR regional office to develop an annual or more frequent summary report focusing on the technical assistance, outreach, and education that office has undertaken in a specific period. The reports should be self-assessments that not only discuss each region's accomplishments, but critically assess all aspects of the region's current efforts, particularly focusing on adjusted plans of action and whether goals were met.

Advertising and publicity, if done effectively, can be important tools in outreach and education strategies to convey OCR's mission and objectives. The Secretary of HHS should provide the necessary resources to update and expand publications and media displays that can then be used more regularly by OCR staff when they participate in conferences and other health care related events.

Finding: In OCR, the Office of Program Operations' Voluntary Compliance and Outreach Division is responsible for coordination of technical assistance, outreach, and education. However, it consists of only two employees, suggesting the low priority of these activities at OCR. Although it monitors these activities, headquarters cannot specify the number of regional staff assigned or the amount of time spent on these

activities. Except for plans and status reports, there is very little exchange of information about these activities between regions and headquarters. There is no liaison person at headquarters who is assigned to the regions for these activities, and headquarters staff are not fully aware of the outreach activities being conducted within the regions. In addition, the regions do not routinely share information with other regions about their outreach, education, and technical assistance activities.¹⁵⁰

Recommendation: OCR should assign headquarters staff to work with the regional offices as full-time outreach and education coordinators (at least one headquarters staff assigned to a region) to monitor and coordinate technical assistance, education, and outreach activities throughout HHS, including the operating divisions. Until HHS/OCR receives additional funds from Congress, the outreach liaison positions should be fully funded by the various HHS operating divisions. The liaison should work with regional offices on a variety of activities, including exchanging information on effective ways of conducting the activities, setting up meetings with regional staff on a regular basis, and evaluating and reporting technical assistance and education activities directly to headquarters with feedback. Finally, the OCR Office of Programs Operations' Voluntary Compliance and Outreach Division should develop a model plan in collaboration with HHS' Healthy People 2010 initiative.

Finding: OCR, for the most part, uses fact sheets to provide information on most of the statutes, including title VI. OCR indicated that these fact sheets have not been updated since the early 1990s. Although the fact sheets are written in languages other than English, including Spanish and some Asian languages, the fact sheets do not clearly describe the role of OCR or provide sufficient information on many of the civil rights laws. For example, the fact sheet on the Hill-Burton Act summarizes the requirement for informing the public of a facility's community service obligations. However, the fact sheet neglects to explain what a Hill-Burton facility is, thus, it is not clear how a beneficiary would know if the services were being provided by a Hill-Burton facility. OCR

states that lack of resources has prevented it from updating the fact sheets and developing other publications.¹⁵¹

Recommendation: OCR needs to redirect some of its resources to update the fact sheets and provide other graphic materials and brochures where fact sheets are not adequate for information. All of the fact sheets should be translated into as many different languages as possible. Input on the form and content should be solicited from all OCR staff, particularly EOS and attorney staff. Brochures, pamphlets, and posters should be distributed to all HHS recipients, requiring that the information be displayed openly for public education.

Finding: OCR's regional offices have the major role in providing technical assistance, and outreach and education to HHS funding recipients, operating divisions, beneficiaries of health care services, advocacy groups, and the general public. However, technical assistance, education, and outreach vary from region to region. OCR indicates that resources dictate where these activities take place (usually in the central city of a region), who receives the assistance and education and in what civil rights area or initiative, how often such activities take place, the amount of staff time spent, and who is responsible for conducting these activities (ranging from the regional manager in one office to the regional attorney in another office to the entire staff of equal opportunity specialists in another office). In some cases, OCR regional staff "piggy back" on operating divisions and other organizations' conferences and activities to get the civil rights message out. In addition to the fact that these activities are not performed evenly across regions, regional staff are not provided adequate, updated training so that they can provide guidance to the public.

In the past, OCR had more contact with community organizations such as the Urban League and La Raza, as well as with beneficiaries and members of other racial and ethnic groups. However, now most of these activities are requested by these groups rather than initiated by the regional offices. Because of its minimal resources and case backlog, OCR has prioritized its outreach according to departmental re-

¹⁵⁰ See chap. 4, pp. 218-19.

¹⁵¹ See chap. 4, pp. 218-19.

quirements, and targeted specific groups for these activities.¹⁵²

Recommendation: Technical assistance, education, and outreach should not be ad hoc activities. While activities should be based on needs and issues specific to a region, the effectiveness and level of staff participation should not vary from region to region. Those regions that have been able to expand guidance and assistance to the public should share strategies with other regions that have not been able to perform these activities at that level. OCR headquarters should sponsor routine, indepth meetings with regional staff on their technical assistance, outreach, and education initiatives so there will be consistent sharing of ideas and strategies for implementing these programs effectively.

OCR must become more creative in finding ways to conduct proactive technical assistance efforts in the face of severe budget constraints. For example, OCR headquarters and regional staff should work in partnership with operating divisions to ensure that OCR's mission and responsibilities are familiar to as many community organizations as possible. OCR should be visible to all community organizations, maintaining a relationship through regular correspondence and initiatives, and also by maintaining a "continuous physical presence" with community and health care organizations throughout the Nation.

Future of OCR's Technical Assistance, Outreach, and Education Program

Finding: OCR outreach and education should extend beyond educating the public to include educating health care practitioners. There is evidence that racial, ethnic, and gender prejudices among physicians may be a problem OCR needs to confront in future outreach efforts. For example, a recently published article reported that doctors are far less likely to recommend rigorous and sophisticated cardiac tests for African Americans and women than for white men with identical complaints of chest pains. The authors of the study could not draw any inferences to overt racism or sex bias in the study, but they suggested that the disparity in treatment may be the result of subconscious perceptions. Because this type of problem may derive in part from a lack of awareness or understand-

ing of minority and women's health concerns among medical practitioners, it is particularly well-suited to outreach and education efforts.¹⁵³

Recommendation: Medical schools should establish courses to make doctors multiculturally literate, and to imbue them with an understanding of the variation in health status and access to treatment between and among populations. OCR should place more emphasis on the scientific research and literature that address the link between health care disparities and the policies and practices of health care providers. OCR should then work with medical schools to develop and promote programs aimed at increasing medical students' awareness of the prejudices that exist in health care delivery. OCR should begin an ongoing dialogue with medical schools to establish mandatory training on race and sex discrimination and civil rights responsibilities in health care.

Chapter 5. The Role of HHS Operating Divisions in Supporting Civil Rights Enforcement Efforts

Summary

Within HHS are 11 agencies, known as operating divisions. Although some operating divisions have functions more obviously related to civil rights than others, all have some civil rights responsibilities through the Federal funds they administer in grants, contracts, and assistance programs. These programs encompass a variety of health related activities and social services, including research, training, and service grants; block grants; cooperative agreements; and health insurance reimbursements, such as medicare and medicaid.

The authority for extramural civil rights enforcement within these programs, however, has been delegated to the Office for Civil Rights, and *not* any of the operating divisions. Thus, OCR has *sole* responsibility for processing and investigating complaints of discrimination under title VI, title IX, Hill-Burton, and the nondiscrimination provisions in block grant statutes, as well as for conducting compliance reviews of recipients of Federal assistance. With respect to operating divisions, OCR is responsible for planning and conducting a continuing program of evaluating civil rights compliance activities; providing lead-

¹⁵² See chap. 4, pp. 219-21.

¹⁵³ See chap. 4, p. 225.

ership and guidance to operating divisions for their civil rights compliance activities; and training operating division staff to carry out their civil rights responsibilities. Because OCR has not delegated the operating divisions any authority to enforce civil rights statutes, the operating divisions' civil rights enforcement depends largely on how OCR and the operating divisions interact in the implementation and enforcement of civil rights laws. However, operating divisions affect OCR's civil rights enforcement efforts when they refer complaints to OCR, ensure that HHS funding recipients are in compliance with civil rights laws before the approval of grants and contracts, and make program and policy decisions, such as on how to distribute funds and what kinds of data reports to require of recipients.

OCR sees the implementation of civil rights statutes as its own responsibility and does not see the operating divisions as having the time, resources or expertise to handle enforcement activities beyond obtaining assurances. However, in recent years OCR staff have begun working more closely with the operating divisions. By OCR accounts, the interaction has increased, is more routine, and serves to ensure that HHS programs are reaching the individuals the programs are intended to serve. But operating division staff did not report OCR and operating division interactions as being so frequent or regular as OCR reported them to be. OCR is not coordinating with the operating divisions on traditional enforcement activities. OCR does work cooperatively with operating divisions during the pregrant process to make sure that recipients and grantees are aware of what they must do. But, HHS has limited the operating divisions' role in enforcement responsibilities to ensuring that recipients provide necessary assurances of nondiscrimination before receiving Federal funds.

How much the operating divisions can affect OCR civil rights enforcement also depends upon their organizational structure, resources, and staffing, as well as on the staff's knowledge and understanding of HHS civil rights regulations, guidance, and requirements for recipients. Without adequate use of resources, operating divisions cannot assist HHS funding recipients in complying with civil rights laws, or perform other civil rights activities that HHS and OCR

deem appropriate. A separate office to address civil rights matters within each operating division would facilitate interaction with OCR staff and support for civil rights enforcement activities, but because only OCR has the authority for civil rights enforcement, none of the operating divisions has an office devoted exclusively to extramural civil rights matters. This has resulted in scattered and sometimes disorganized efforts to address civil rights matters.

Regional structure may also affect operating divisions' ability to engage in civil rights enforcement. For example, because the Health Care Financing Administration (HCFA) has some extramural civil rights responsibilities, its staff have more reason than other operating divisions to interact with OCR staff. Most of the interaction between HCFA and OCR staff takes place at the regional level. HCFA has 10 regional offices, most of which are located in the same buildings as HHS regional offices, thus facilitating interactions between the two staffs. Yet HCFA interaction with OCR is limited, and only two HCFA regions had one or more full-time employees devoted to civil rights activities. The lack of proximity of some operating divisions' and OCR's regional offices precludes casual, day-to-day encounters between the two staffs and could restrict interactions on more formal activities. Overcoming these barriers will require additional efforts when these operating divisions need training, technical assistance, or other OCR contact.

In many cases, the operating divisions have failed to demonstrate awareness and understanding of civil rights documents developed and provided by OCR. Although the lack of the operating divisions' awareness of OCR documents is disturbing, the information contained in these documents is not very helpful to operating division staff or their recipients in understanding compliance or how to achieve it. As a result, operating divisions have sometimes developed better documents on their own. For example, NIH provides a how-to guide in the "Outreach Notebook for the NIH Guidelines on Inclusion of Women and Minorities as Subjects in Clinical Research." It contains advice on how to establish and maintain communication with participants, their families, and communities to better include women and minorities in research studies. However, leadership for developing guidance should

come from OCR to ensure that all operating divisions provide such guidance to funding recipients.

Although their organizational structures, staffing, and levels of interaction with OCR may not be conducive to conducting civil rights activities, several of the operating divisions are performing some extramural civil rights functions. OCR can delegate extramural responsibilities for enforcing civil rights among recipients of grants and contracts to the operating divisions through a memorandum of understanding (MOU). An MOU is appropriate for operating divisions to collect additional information on grant applicants' past civil rights performance before making awards. However, few operating divisions have an MOU with OCR, and such MOUs do not satisfactorily address civil rights responsibilities. For example, the 1979 MOU between OCR and HCFA delegates broad extramural responsibilities for enforcing civil rights among recipients of grants and contracts and states ways in which OCR will support HCFA. It does not mention preaward, postaward, or onsite reviews of compliance, nor does it direct HCFA to collect information that OCR might use for such reviews. At the same time, HCFA has done very little to meet the responsibilities stated in it, such as assessing recipients' needs for technical assistance. An MOU can have advantages for operating divisions as well as for OCR. However, the broad language of HCFA's longstanding MOU may not be the best model. It is unclear how much responsibility is delegated to the operating division. But, regardless of the language, the HCFA MOU appears to be of little consequence because neither HCFA nor OCR are carrying out many of the responsibilities agreed to in the document.

Apart from any formal agreement with OCR, the operating divisions' only authorized extramural civil rights enforcement responsibility is obtaining the assurance of civil rights compliance from recipients. Before providing Federal assistance, operating divisions are required to ensure that the appropriate civil rights forms in the application packets for Federal financial assistance are submitted to OCR. The assurance forms provide an itemized list of civil rights laws and require a signature of confirmation that the organization will comply with all Federal statutes relating to nondiscrimination. Operating division staff lack the authority to do any followup after the assurance of compliance has

been received. Similarly, during the postaward stage, when the operating division's program staff conduct site visits to determine the progress of recipients in carrying out their health-related missions, they are not expected to investigate recipients' compliance with civil rights statutes or complaints of discrimination.

Apart from the certificate of assurance, application packages address civil rights issues in other ways. The National Institutes of Health (NIH) application package includes a form for personal information, including race/ethnicity, on the principal investigator or program director and a policy statement on the inclusion of minorities and women. The form states that the personal information on the grantee is used to monitor any inequities in the review and award processes and is separated from the grant application before the review process so that it does not influence the process of awarding funds. It is unclear whether NIH or any other operating divisions are routinely analyzing such information.

The NIH research grant application also states that women and minorities must be included in research protocols. If minorities and women are not included, a clear and compelling rationale and justification must establish that inclusion of women and minorities is inappropriate with respect to the health of the subjects or the purpose of the research. Application instructions state that grantees must report annual enrollment of women and men and the race and ethnicity of research participants. However, it is unclear whether the reports are used to review compliance of individual grantees.

OCR expects operating division staff to be aware of civil rights statutes and to refer suspected violations to OCR. But, the role that OCR intends for operating divisions is limited to ensuring that grant applicants receive the appropriate application forms and submit civil rights assurances. Only a few operating divisions have moved beyond that limited role. For example, the Substance Abuse and Mental Health Service Administration's (SAMHSA) Office of Equal Employment Opportunity and Civil Rights assisted OCR in its major outreach and education campaign on LEP guidance. In addition, Health Resources and Services Administration (HRSA) has a policy on monitoring civil rights compliance of federally assisted recipients and conducts a small number of onsite audits to ensure

compliance when reviewing, awarding, and monitoring their contracts and grants. These activities appear to be done without OCR's delegation of authority or any other formal understanding and suggest the need for OCR intervention to ensure a clear, formalized delineation of roles and responsibilities.

HCFA strives to guarantee equal access to health care in its medicare and medicaid programs by assuring all individuals the opportunity to have their health care needs met with the best health care that can be provided, regardless of location, income, or other circumstances. The operating division has numerous ways of doing this. For example, in 1994 and again in 1998, HCFA issued a Civil Rights Compliance Policy Statement expressing a commitment to ensuring that there is no discrimination in the delivery of health care services under HCFA programs. The statement was shared with contractors, State agencies, health care providers, and others who administer HCFA programs. Equal access to health care can also be monitored through HCFA's data collection system which records beneficiaries' race and ethnicity. However, HCFA does not have definitive information on the race or ethnicity of every claim because the medicaid program is a Federal/State program and HCFA cannot require States to adjust their data collection systems.

Once a grant is approved, HCFA has a grants management system to ensure compliance with Federal laws, regulations, and policies; however, civil rights compliance is not an explicit part of this system. HCFA appoints program and grant management officials to each grant to address programmatic, scientific, and/or technical aspects, to provide business or other expertise in nonprogrammatic areas of grants administration, and to ensure that the grantee fulfills requirements of laws, regulations, and administrative policies. Notably, collecting information about the number or percentage of minorities and women who are employed or served by grantee organizations is not stated as responsibilities of these officials.

Finally, the authorities that OCR and the operating divisions have to monitor the civil rights compliance of recipients is somewhat different for block grant programs than it is for other grants and cooperative agreements. With respect to block grant programs, OCR has no

line authority over the activities of operating divisions. Without OCR involvement, operating divisions that sponsor State-administered block grant programs may have difficulty providing civil rights guidance to State recipients on, for example, compliance or methods of administration to ensure subrecipients' compliance. HHS requires its State recipients to submit methods of administration specifying their procedures in assessing, maintaining, achieving, and ensuring their own and subrecipients' compliance, but operating divisions do not (and are not required to) review the submitted methods or monitor States' adherence to such procedures.

Authority for Civil Rights Enforcement

Finding: The Secretary's delegation of authority makes it clear that HHS' Office for Civil Rights, not the operating divisions, is responsible for compliance and enforcement activities relative to civil rights statutes. However, OCR has acknowledged that it is not able to conduct all necessary compliance activities because of the severe budget restraints under which it operates. Based on the Commission's study of civil rights in the health care setting, it is very clear that there is a significant problem in educating recipients of Federal funding about their responsibilities under the civil rights statutes OCR enforces, particularly the older ones such as title VI, Hill-Burton, and title IX.¹⁵⁴

A 1993 report of the HHS Civil Rights Review Team found a lack of a relationship between OCR and the operating divisions. OCR's review activities were not meaningfully integrated into operating division program management functions. OCR guidance to the operating divisions tended to be informal. OCR did not have an oversight and monitoring system to review, evaluate, and direct the operating division performance in civil rights compliance activities. In short, OCR and the operating divisions did not share responsibilities for enforcement of civil rights statutes (i.e., complaints investigations, compliance reviews, and obtaining assurances of compliance) and broader civil rights issues such as identifying discriminatory practices or systemic discrimination and implementing approaches for prevention or resolution of problems. The report suggested that OCR use oper-

¹⁵⁴ See chap. 5, p. 229.

ating divisions to obtain detailed information on grant applicants' past civil rights performance, carry out pregrant reviews of recipients' self-audits; gather information for OCR reviews; and audit activities in the course of monitoring civil rights compliance. The report also recommended that OCR notify operating divisions of complaints filed against grantees and the final findings and solicit their help in identifying problematic trends, and that OCR and operating division experts collaborate in identifying strategies to address systemic discrimination.¹⁵⁵

Because the operating divisions are responsible for administering regulations, grants, contracts, and programs covered under the statutes, they can have enormous impact on the effectiveness of OCR's civil rights enforcement efforts. Yet there is no uniform system at the Department to ensure that all operating divisions are meeting civil rights responsibilities effectively. Generally, some operating divisions do not have a system for referring complaints to OCR and do not know how many total complaints are filed within OCR. There is no coordinated system for conducting preaward reviews, and very little coordination with OCR concerning these reviews.¹⁵⁶

Recommendation: Optimally, OCR must have additional resources in order to effectively enforce civil rights laws in the health care context. Additional staff are needed for OCR to conduct compliance reviews of *all* applicants for and recipients of HHS funding. OCR's budget should be increased to at least \$40 million in order for OCR to sufficiently conduct compliance reviews, investigations, and other civil rights enforcement activities. However, because of the persistent budgetary problems experienced by OCR and the current political climate, it appears unlikely that OCR will receive such a significant increase in the near future. Absent an increase in OCR's budget, operating divisions could transfer funds to OCR for additional full-time employees to enforce civil rights in programs funded by operating divisions.

A third alternative would be to delegate specific civil rights enforcement activities to civil rights units within the operating divisions, through a delegated directive from the Secretary. With appropriate OCR oversight, the oper-

ating divisions could conduct most civil rights enforcement activities. However, in order to conduct complaint investigations and full-scope compliance reviews and develop methods of administration and policy guidance, significant OCR oversight would be required. OCR and the operating divisions should review the extramural civil rights responsibilities and activities currently conducted by operating divisions and determine the extent to which civil rights enforcement activities could be delegated to operating divisions.

All delegated enforcement activities should be handled by a separate civil rights unit in each operating division. Each civil rights unit should be staffed by a minimum of 25 employees, including a civil rights manager. All new staff hired for the operating divisions' civil rights offices should be certified by OCR to conduct civil rights related job functions. However, creating a separate civil rights office within each of the operating divisions could cause a potential disjunction in the enforcement and monitoring of civil rights. To prevent this, the operating division offices must be required to report directly to OCR headquarters and will be subject to all policies and rules established by OCR headquarters. All activities of such units must be closely monitored and reviewed by OCR. Any correspondence to applicants and recipients concerning civil rights compliance must be reviewed and effected by the director of OCR.

In addition, OCR should set forth standards and guidelines for a uniform system of civil rights responsibilities and coordination of civil rights activities, where possible, within the operating divisions. Operating divisions' civil rights staff must be trained sufficiently in civil rights laws and investigative techniques. There also should be ongoing oversight of operating division civil rights staff by OCR. For each operating division, OCR should assign staff members to act as a liaison between OCR and the civil rights staff of each operating division. In this way, all enforcement issues can be coordinated through OCR.

OCR remains ultimately responsible for HHS' implementation and enforcement of title VI. As such, the director of OCR must directly guide the operating division activities related to title VI and other external civil rights enforcement. To effectuate such guidance, OCR should first de-

¹⁵⁵ See chap. 5, pp. 255-56.

¹⁵⁶ See chap. 5, pp. 239-54.

velop comprehensive procedures or instructions for the enforcement authority delegated to the operating divisions. These procedures should instruct the operating division staff to conduct the specific mechanisms assigned them, such as desk audit compliance reviews. Second, OCR must establish a thorough oversight and monitoring system to review, evaluate, and direct operating divisions' performance related to those compliance functions. As part of this system, operating divisions should be required to report specific activities on a quarterly basis; and, OCR should regularly review and evaluate Operating division staff efforts; regularly assist and train operational staff; and provide agency policy guidance and general legal and regulatory guidance as necessary. Such a system will enable OCR to effectuate necessary changes in the operating divisions' responsibilities and practices when problems in title VI implementation and enforcement are discovered at the operational level.

Finding: OCR has various levels of interaction with the operating divisions. In at least one instance, this interaction has been formalized with a memorandum of understanding (MOU). For example, the MOU between OCR and HCFA delegates broad extramural responsibilities for enforcing civil rights among recipients of grants and contracts. Yet it is unclear precisely how much responsibility has been delegated to HCFA.¹⁵⁷

However, OCR does not have formal agreements with most of the operating divisions within HHS. Nonetheless, it appears that some of the operating divisions informally engage in civil rights compliance activities. For example, in 1998 SAMHSA's EEOCR office was formed to include external civil rights functions, yet there currently is no formal MOU or other agreement between OCR and SAMHSA defining exactly what external civil rights activities SAMHSA's EEOCR office should perform.¹⁵⁸

Recommendation: MOUs with operating divisions could facilitate OCR's civil rights enforcement activities in a number of important ways. To the extent that operating division staff are conducting informal civil rights related activities, OCR must formalize these activities through a delegated agreement clearly specifying

ing the *exact* external enforcement activities for which an operating division has responsibility, whether complaints referral, preaward reviews, or other enforcement activities. OCR should enter into memoranda of understanding with operating divisions, and update the MOUs already in existence. OCR should use these memoranda of understanding to formalize the role of the operating divisions in conducting civil rights related activities, particularly those activities that operating divisions already perform. OCR also should use these delegated agreements to ensure a higher level of quality in its civil rights enforcement operations.

Each MOU should include provisions detailing the civil rights aspects of each operating division's operations, including goals for specific initiatives. Through the establishment of guidelines and procedures, an MOU should also ensure a higher quality of operating division response with respect to referrals of civil rights violations to OCR. Specifically, an MOU should include specific instructions on what kinds of information are useful in making an assessment as to whether a recipient is engaging in discriminatory conduct. In addition, each MOU should provide guidelines for better implementing compliance requirements such as preaward assurances. For example, operating division staff should conduct meetings with recipients to ensure that they fully understand assurances' compliance requirements.

To be effective, an MOU should be clear in outlining the responsibilities of OCR and the operating division to ensure that the civil rights responsibilities are workable, compatible, and achievable. It should include mechanisms for evaluating the implementation of the requirements and responsibilities for effectiveness. Any MOU should be written so that it can be updated to reflect changes in the laws' provisions and coverage. The MOU agreement should facilitate regular interaction about civil rights matters between the operating division and OCR. It should clarify the communication lines between what is expected from both the operating division and OCR with respect to compliance activities and complaints information. The negotiation process between operating divisions and OCR to formulate an MOU should be a continuous and regular exchange between the two entities to share ideas and recommendations. Finally, after

¹⁵⁷ See chap. 5, pp. 240–42

¹⁵⁸ See chap. 5, p. 250.

the MOU is developed, meetings between OCR and operating division staff concerning the implementation of all responsibilities in the MOU should be held routinely to assess how the MOU's provisions are being implemented and how the implementation can be improved.

Finding: The current MOU between HCFA and OCR, signed in 1979, does not mention preaward, postaward, or onsite reviews of compliance, nor does it direct HCFA to collect information that OCR might use for such reviews. At the same time, HCFA does very little to meet the responsibilities stated in the agreement, such as assessing recipients' needs for technical assistance. Further, although the MOU states ways in which OCR will support HCFA, OCR is doing very little to carry out its responsibilities to HCFA. However, HCFA's civil rights staff are hoping to do more on extramural civil rights and plan to negotiate a new MOU with OCR with more clearly stated responsibilities, including some means by which HCFA can expedite OCR complaints processing and compliance reviews.¹⁵⁹

Recommendation: HCFA's 1979 MOU needs to be revised and updated. OCR should negotiate a new MOU with HCFA to clearly define the responsibilities of each agency. The language of the MOU should clearly state the enforcement duties that are delegated to the operating division. Furthermore, any activities delegated to HCFA should be tailored to the staffing and resources that the operating division has to perform them. The MOU also should specify OCR's responsibilities in relation to HCFA. With these required elements, the memorandum of understanding between HCFA and OCR could be used as a model for the development of civil rights offices and responsibilities within other operating divisions.

Implications of Operating Division

Organization for HHS Civil Rights Enforcement

Finding: The Commission found that none of the operating divisions has an independent civil rights staff for external civil rights activities. Some operating divisions transfer such responsibilities to their grants management office. Four operating divisions have offices that appear to address extramural civil rights; however, these offices focus primarily on equal employment op-

portunity (EEO) matters, and the mission of these offices with respect to title VI, title IX, Hill-Burton, and nondiscrimination provisions of block grant statutes is unclear.

Further, operating divisions that have offices which include extramural civil rights have few staff devoted to extramural matters. For example, FDA and SAMHSA do not have full-time positions devoted to extramural civil rights matters; instead, civil rights responsibilities are incorporated into the job functions of one staff member in each office. HCFA, which had additional delegated responsibilities, had three staff who were assigned extramural responsibilities. Among HCFA regions, two regions had one or more full-time employees devoted to civil rights activities; the rest had half or less of a full-time staff position spent on civil rights and related activities. No other operating division appeared to have regional staff engaged in extramural civil rights activities.

The current number of operating division staff assigned extramural duties is insufficient for operating divisions to engage in enforcement activities such as conducting pre- or postaward reviews or site visits of funding recipients. With such low staffing levels, operating divisions are limited to obtaining civil rights assurances. They also are very limited in the ways in which they can incorporate extramural civil rights concerns into program and policy decisions. At best, operating divisions can do little beyond designating an OCR liaison.¹⁶⁰

Recommendation: Barring an increase in OCR's budget, all operating divisions should redistribute funds to establish separate civil rights units within them. Civil rights and EEO responsibilities should be separated through the establishment of a separate civil rights unit in each operating division. Further, operating divisions should review mission and functions of existing offices with civil rights responsibilities to ensure that extramural activities are included. Mission and function statements should provide for any additional civil rights responsibilities incurred by signing an MOU or other agreement with OCR. Operating divisions should also review the position descriptions of staff assigned to extramural activities and revise them to reflect extramural duties. All activities of operating divi-

¹⁵⁹ See chap. 5, pp. 240-43.

¹⁶⁰ See chap. 5, pp. 234-54.

sion civil rights offices should be monitored and reviewed by OCR staff.

Operating divisions also should review staffing levels in light of their extramural civil rights activities and add staff as appropriate. They should not sign MOUs or other agreements that obligate them to additional responsibilities that their staff levels cannot support. Operating divisions must either assign staff to separate civil rights units, or fund additional full-time employees within OCR for civil rights enforcement activities.

Civil Rights Enforcement Responsibilities of Operating Divisions

Finding: Because the preaward review is OCR's responsibility, most operating division staff currently do not request applicants' data on the racial/ethnic and gender characteristics of the population eligible to be served, examine prospective recipients' record with respect to compliance reviews conducted during previous years, or obtain information on whether applicants have been found in noncompliance with civil rights laws in recent years. Yet a recent HHS review team recommended that the operating divisions collect information regarding the applicant's current or past civil rights compliance along with their assurance of compliance with civil rights laws.

However, forms that could be used as a self-audit currently exist and might be adapted to be part of the funding application. For example, OCR is pilot testing an automated pregrant review data request project for HCFA's medicare program. Similarly, OCR and HRSA staff in Region X have entered into a partnership and have developed a civil rights self-assessment for providers to use voluntarily. Some grantees found the self-assessment useful in reminding them that their signature on the assurance form implies provision of health services in a nondiscriminatory manner, in raising their awareness of civil rights issues and requirements, and in showing them new, cost effective ways of serving patients consistent with civil rights regulations.¹⁶¹

Recommendation: Preaward reviews should be conducted for *all* applicants for Federal funding. Operating division staff should collect data on the racial/ethnic and gender characteristics of the population eligible to be

served by applicants, and obtain information on prospective recipients' records with respect to compliance reviews and noncompliance with civil rights laws in recent years. Such reviews should be conducted by operating division staff within a separate civil rights unit, or operating divisions should transfer funds to OCR for this and other civil rights enforcement activities.

OCR should continue developing its automated pregrant review data request project and should expand it to other programs and other operating divisions. In particular, self-audit guidance should be provided to all recipients of HHS funding. OCR should review HRSA's civil rights self-assessment guide for its usefulness with other providers and other operating divisions. OCR should also issue a formal agreement with HRSA to support the experimental use of this document. Recipients should be encouraged to conduct self-audits and maintain such information in regards to compliance for future compliance reviews.

Finding: A grants management system offers a mechanism through which operating divisions can easily collect information on civil rights compliance. For example, once a grant is approved, HCFA has a grants management system to ensure compliance with Federal laws, regulations, and policies; however, civil rights compliance is not an explicit part of this system. HCFA appoints program and grant management officials to each grant to address programmatic, scientific, and/or technical aspects, to provide business or other expertise in nonprogrammatic areas of grants administration, and to ensure that the grantee fulfills requirements of laws, regulations and administrative policies. A grants policy officer has oversight of grants operations, issues policies, and conducts technical assistance and training for HCFA staff and grantee organizations. He or she is to conduct onsite compliance reviews of grantee organizations and studies to determine the need for changes in policies or to develop and test innovative policies and procedures. Notably, collecting information about the number or percentage of minorities and women who are employed or served by grantee organizations is not stated as responsibilities of these officials.¹⁶²

¹⁶¹ See chap. 5, pp. 239–45.

¹⁶² See chap. 5, pp. 250–53.

Recommendation: Current grants management activities should be expanded to incorporate the collection of civil rights enforcement data. Officials who currently conduct onsite compliance reviews of grantee organizations with respect to other grants administration issues also could obtain information on civil rights compliance. The number or percentage of minorities and women the grantee organization employs or serves, written affirmative action policies, and information on complaints filed against the organization are some of the information that could be collected and provided to OCR or operating divisions' civil rights units.

Finding: With respect to block grant programs, OCR has no line authority over the activities of operating divisions. HHS requires its State recipients to submit MOAs specifying their procedures assessing, maintaining, achieving, and ensuring their own and subrecipients compliance, but operating divisions do not (and are not required to) review the submitted MOAs or monitor States' adherence to such procedures. OCR itself has provided little guidance to States concerning MOAs, and does not have a regular program for reviewing States' and their subrecipients' compliance with civil rights laws. Without OCR involvement, operating divisions that sponsor State-administered block grant programs may have difficulty providing guidance to State recipients on ensuring subrecipients' compliance with civil rights laws.¹⁶³

Recommendation: OCR must ensure that State recipients of HHS funding, and their subrecipients, are complying with civil rights statutes. Lacking sufficient staff and funds to conduct annual reviews of recipients of block grant funds, OCR must develop a mechanism by which operating division civil rights staff systematically review and monitor State-administered block grant programs. OCR should develop training materials and conduct training of operating division staff and their recipients on MOAs, civil rights responsibilities, and ways of assessing and achieving compliance. The procedure should include States filing annual reports with the operating division civil rights units on their and their subrecipients' compliance with applicable civil rights laws. Operating division civil rights staff should review the reports and

develop plans for conducting compliance reviews. OCR should review and approve all State reports and compliance reviews. All compliance activities must be monitored by OCR.

Finding: Currently, there are no written procedures concerning the forwarding of discrimination complaints to OCR. In some instances, civil rights complaints are referred to OCR from district and regional offices of operating divisions, or complaints are sent directly to OCR by complainants. Thus, operating division headquarters staff are unaware of complaints that have been filed against their recipients. To address this problem, FDA staff would like an MOU with OCR that requires OCR to inform the FDA civil rights staff when OCR receives an FDA complaint from one of these other offices.¹⁶⁴

Recommendation: OCR should develop a mechanism for ensuring that all complaints of discrimination are forwarded to OCR. At the same time, OCR should recognize that operating divisions want more information about complaints filed against their recipients. OCR should explore processes for routinely providing operating divisions information on the status of complaints against their recipients. OCR should develop a complaints tracking system that can provide information on the facilities against which complaints have been filed, as well as other information about the investigation, including the outcome of the investigation. Such a system would require the collection of expanded data on HHS funding recipients and applicants. For example, OCR should have information on all HHS recipients, and the programs and/or operating divisions that funded them. This information should be maintained in a database that can be cross-referenced to the complaints tracking system, so that when a complaint is filed, the information concerning the source of funding is readily available. In this way, OCR will be able to determine which operating division provided the funding and can report any complaints and violations to that operating division.

In addition, this tracking system should include information on the assurance forms signed by applicants' organizations. OCR should track the organizations and institutions that have signed such forms, civil rights contact persons in those organizations and institutions, and dates

¹⁶³ See chap. 5, pp. 254–55.

¹⁶⁴ See chap. 5, pp. 239–45.

such forms were signed. Maintaining accurate, up-to-date records on HHS funding recipients and maintaining constant communication with recipients is crucial not only for conducting compliance reviews, but also for demonstrating the seriousness of OCR's mission with respect to health care. OCR must become a known presence in the health care industry so that recipients and beneficiaries understand and know where to get information concerning the application of civil rights laws to health care. This database could also be a useful reference tool for future funding—before an application is approved, OCR and the grant-making entity can check to see if a recipient has a history of violations.

Finding: Most operating divisions' only extramural enforcement responsibility is obtaining the assurance of civil rights compliance. Before providing Federal assistance, operating divisions are required to ensure that the appropriate civil rights assurance forms have been submitted to OCR. The assurance forms require an official of the applicant organization to attest that the organization will comply with all Federal statutes relating to nondiscrimination. However, not all of the operating divisions use the same forms for applying for Federal assistance, and some forms appear to be outdated. Thus, applicants to the various HHS programs probably do not receive the same information concerning their civil rights responsibilities.¹⁶⁵

Recommendation: OCR should verify that all operating divisions are using the application forms that provide standardized information on civil rights requirements. This will ensure that applicants receive the most current instructions regarding any civil rights guidance and reporting requirements. OCR also should revise the assurance form itself to better describe the need for applicants' organizations to assure that they will comply with civil rights laws, to make clear to applicants HHS' authority to conduct reviews of such compliance, and to indicate the penalties for failure to comply with the laws.

In addition to assurance forms, OCR should develop technical assistance materials concerning the importance and application of civil rights requirements to the health care industry. OCR also should develop a brief summary of its role and how it can be contacted for further informa-

tion and technical assistance. Such information, as well as OCR's civil rights fact sheets, should be included in all application packets.

In addition, OCR should provide properly trained operating division staff appropriate resources and guidance for conducting civil rights compliance activities. For example, OCR staff should prepare a questionnaire to accompany the preaward assurance statement. This questionnaire would be designed to elucidate information from the proposed grantee about its civil rights record. Operating division staff could then conduct a preliminary review of the response and forward it to OCR with an appropriate recommendation.

The Extent of OCR's Leadership Role over the Operating Divisions

Finding: The 1994 OCR Strategic Plan did not directly address civil rights issues in, and responsibilities of, the operating divisions. Although OCR did consult with the operating divisions in developing its strategic plan, and planned to expand partnerships for civil rights awareness, it failed to incorporate operating division involvement in preaward reviews and other civil rights enforcement activities.¹⁶⁶

Recommendation: OCR should continue interacting with operating divisions in developing its strategic and annual plans; seeking their input into program priorities to address discrimination, expanding partnerships for civil rights awareness; and developing civil rights guidelines and customer outreach. It should also explore ways in which civil rights responsibilities can be better shared with operating divisions. In short, OCR should reexamine the 1993 Civil Rights Review Team's report for overlooked suggestions on how to better enforce civil rights compliance, both through streamlining its own enforcement processes and through assistance from the operating divisions.

Finding: Recently, OCR staff have begun working more closely with the operating divisions. By OCR accounts, the interaction has increased, is more routine, and serves to ensure that HHS programs are reaching the individuals the programs are intended to serve. But operating division staff did not report OCR and operating division interactions as being so frequent

¹⁶⁵ See chap. 5, pp. 249–55.

¹⁶⁶ See chap. 5, p. 257.

or regular as OCR reported them to be. Some of the recent increase in interaction between OCR and operating divisions may be because operating divisions have expanded their EEO offices to include extramural civil rights components and begun to negotiate for additional responsibilities through MOUs. OCR appears to work more frequently with some operating divisions than others. For example, FDA's OEECR reported receiving only minimal technical assistance and guidance from OCR, usually only when new or novel issues arose. The OEECR director would like more regularly scheduled meetings with OCR. HCFA's OEOCR recently has had much interaction with OCR as a result of a massive training effort. OEOCR's director hopes to sustain intensive OCR interaction when the training is completed. On the other hand, SAMHSA found OCR technical guidance and assistance readily available when the extramural civil rights component was added to its office functions.¹⁶⁷

Recommendation: OCR should continue to strive to provide more technical assistance to operating divisions. OCR should develop an annual training plan and training materials designed specifically for operating division staff. Further, OCR should assign a headquarters staff member to be responsible for civil rights issues relating to each operating division. These staff members would act as liaisons between the operating division civil rights units and OCR. In so doing, these OCR operating division liaisons would provide training and technical assistance to operating division staff, oversee civil rights compliance activities of the operating divisions, and coordinate information concerning the recipients receiving funding from the operating divisions. Also, each operating division should designate a staff person in its civil rights office to act as a liaison with OCR, meeting regularly and exchanging information with OCR staff.

Finding: OCR does not have a formal oversight and monitoring system to review, evaluate, and direct the performance of operating divisions as it relates to their extramural civil rights activities. Guidance to the operating divisions on such matters tends to be on an informal basis. Increased interaction between operating divisions and OCR appears to be based on the amount of an agency's extramural civil rights

activities and the negotiation of additional civil rights responsibilities through MOUs.¹⁶⁸

Recommendation: OCR should take the leadership role in providing guidance and training to operating divisions in carrying out any MOU or agreement with respect to compliance activities. It should be OCR's responsibility to monitor, review, and provide feedback to operating divisions on their extramural civil rights activities, as well as involve operating divisions in identifying strategies to improve such activities. The relationship between the operating divisions and OCR should not be based on proximity, negotiation of an agreement, or the extent of operating divisions' compliance activities.

Operating Divisions' Awareness of Civil Rights Regulations and Guidance

Finding: In many cases, operating divisions failed to demonstrate an awareness and understanding of the civil rights documents and policies developed by OCR. Further, OCR civil rights documents are not very helpful to operating division staff or their recipients in explaining civil rights compliance or how to achieve it. Operating divisions have sometimes developed better documents on their own. Yet, when an operating division develops a useful document, such as the *NIH Grants Policy Statement*, other operating divisions remain unaware of it and may continue using less current documents. NIH has an "Outreach Notebook" containing advice on how to establish and maintain communication with participants, their families, and communities to better include minorities and women in research studies which might be helpful to other operating divisions that fund research. But, NIH does not have the authority to impose their policy statement on other operating divisions, and other operating divisions use the less recent PHS Grants Policy Statement even though the NIH Grants Policy Statement is an improvement.¹⁶⁹

Recommendation: OCR should assume a leadership role in developing guidance for operating divisions and their recipients. The guidance should go beyond explaining regulations and where victims of discrimination should file their complaints. It should identify strategies for providers and other funding recipients to

¹⁶⁷ See chap. 5, pp. 255-62.

¹⁶⁸ See chap. 5, pp. 239-55.

¹⁶⁹ See chap. 5, pp. 235-39.

achieve compliance. OCR should examine existing operating division guidance and encourage other operating divisions to use or adapt helpful documents.

Operating divisions should make sure that they are informing providers and funding recipients of the most recent policy statements and guidance on civil rights compliance. They should consider including self-audit forms or other documents that aid providers and recipients in assessing their own civil rights compliance and suggestions for outreach procedures to increase the participation of minorities and women. Operating divisions should seek OCR and other operating division input in developing such guidance.

OCR must provide training for operating divisions to familiarize them with the civil rights guidance that OCR provides, including regulations, policy guidance, civil rights fact sheets and pamphlets, and training materials. All operating divisions should receive the documents, as well as training on the meaning of the documents and how the information should be shared with recipients and beneficiaries. There should also be a feedback mechanism so OCR can assess whether these documents are understandable to lay persons.

All OCR materials, including regulations, guidance, and technical assistance documents, should be part of OCR training tools and resources. OCR must assign staff to produce relevant policy documents and research issues affecting health care, such as managed care.

Finding: OCR lacks a policy on providing civil rights training to operating division staff. The headquarters office does not routinely train operating division staff. Instead, regional OCR offices conduct training sessions for operating division regional staff. Further, OCR lacks any means of assessing training needs. OCR does not formally or regularly assess the deficiencies in operating division staffs' civil rights knowledge or skills. Finally, OCR does not even have training materials to disseminate. Instead of a comprehensive training manual, OCR relies upon the *Case Resolution Manual*, which needs to be supplemented with more formal training.

According to OCR staff, OCR is trying to make operating divisions more aware of civil rights issues so they can target their programs to address such issues. OCR guidance, technical assistance, outreach to operating division fund-

ing recipients, and training are some ways to do so. Although OCR has made some effort in these areas, they have been piecemeal and have not met operating division needs. Finally, although the Secretary clearly delegated training operating division staff on civil rights to OCR, OCR has not offered departmentwide training since 1993. Since then, training has not covered all civil rights statutes or been available to more than one operating division at a time.¹⁷⁰

Recommendation: OCR should formulate a written policy that requires training of operating division staff on civil rights matters on a regular basis. This policy would require OCR to provide training and technical assistance as part of its operations. In addition, similar departmentwide, intensive civil rights training and technical assistance activities that were offered in 1993, and at HCFA during 1999, should be sponsored by OCR more regularly, and not initiated solely at the request of an operating division. The Department should make resources available so that OCR staff can travel to operating divisions' regional and/or cluster offices to offer these services.

Moreover, OCR should develop an assessment to identify training needs of OCR staff at headquarters and in the regions, as well as of operating division staff. The assessment should be part of a routine procedure to identify training needs and provide and evaluate the training. OCR should make sure that their regional staff are adequately trained to offer appropriate technical assistance to operating divisions' regional staff. At the same time, OCR should monitor the extent to which regional staff provide operating divisions technical assistance to know when training is needed.

Further, OCR should develop a technical assistance guide and other training materials that address not just complaints and compliance reviews, but also outreach for minorities and women, and other ways to achieve compliance. The materials should be disseminated to all operating divisions and through them to providers and recipients.

Organization of Operating Divisions

Finding: The amount of interaction between operating divisions and OCR varies depending

¹⁷⁰ See chap. 5, pp. 261–62.

on the proximity between operating divisions' regional offices and OCR regional offices. The lack of proximity influences the frequency and formality of the interaction, even for certain critical activities such as training and technical assistance. Regional structure may affect operating divisions' ability to engage in civil rights enforcement. Much of HCFA's interaction with OCR staff takes place at the regional level. Most of HCFA's 10 regional offices are located in the same buildings as HHS regional offices, thus facilitating interactions between the two staffs. Yet HCFA and other operating division interaction with OCR is limited by the small number of regional staff with extramural responsibilities. Furthermore, not all operating divisions have a regional office structure that provides easy opportunities for interaction with OCR regional offices. Some operating divisions lack proximity with OCR's regional offices, which precludes casual, day-to-day encounters between the two staffs and could restrict interactions on more formal activities.¹⁷¹

Recommendation: Operating divisions that are to carry out extramural activities with recipients must have the regional staff and structure to do so. They should consider ways to increase interaction with OCR on extramural civil rights matters, including the proximity of their offices to OCR regional offices. In particular, operating divisions that do not have standard regional structures, should make additional efforts to overcome barriers to interaction with OCR, such as by scheduling more frequent training or technical assistance.

Recipients of HHS Funds

Finding: The assurance of compliance form is signed by an authorized official of the organization receiving Federal funds. Thus, the employees of the organization who provide health care services or conduct health research are not directly informed by OCR of their responsibility to comply with civil rights laws, nor are they held accountable for violations of civil rights laws. There is no mechanism to guarantee that such individuals are even informed of the laws that are applicable to the services they provide.¹⁷²

¹⁷¹ See chap. 5, pp. 231–35.

¹⁷² See chap. 5, pp. 245–48.

Recommendation: As a requirement of receiving Federal funds, OCR should require *all* recipients to designate a civil rights coordinator. This coordinator would be responsible for ensuring that employees of the recipient are knowledgeable of and comply with title VI, title IX, the Hill-Burton Act, civil rights provisions of block grant statutes, and other applicable civil rights laws. OCR should specify minimum responsibilities of the civil rights coordinators, which should include:

- Monitoring agreements (grants, loans, contracts, etc.) with HHS to ensure compliance with civil rights laws.
- Coordinating OCR compliance reviews for the organization.
- Providing data to OCR and/or State agencies for the purposes of ensuring compliance with civil rights requirements.
- Educating employees of the organization on civil rights issues and responsibilities.
- Providing information to patients and beneficiaries concerning their civil rights.
- Working with organizational programs and entities (legal and policy offices, emergency room staff, researchers, etc.) to ensure that civil rights responsibilities are understood and incorporated into all activities of the organization.
- Working with OCR to obtain technical assistance and educational materials, as needed.
- Acting as a liaison between the organization and OCR and other civil rights organizations.

OCR must certify this coordinator as having the appropriate training and job responsibilities to occupy this position. OCR must recertify the coordinator every 5 years, and verify annually that the individual responsible for acting as the coordinator has not been replaced. In certifying the coordinator, OCR must consider the coordinator's placement within the organizational structure of the organization. For example, the civil rights coordinator should not be located in the human resources office or have equal employment responsibilities.

National Institutes of Health

Finding: The NIH application package includes a form for personal information on the principal investigator or program director, ask-

ing for his or her age, gender, and race or ethnic origin. The form states that this information is used to monitor any inequities in the review and award processes and is separated from the grant application before the review process so that it does not influence the process of awarding funds. It is unclear whether NIH or any other operating divisions are routinely analyzing such information.¹⁷³

Recommendation: NIH (and any other operating division that funds research) should routinely report and monitor the numbers of minority and women researchers who apply for and receive funding for research. This information is crucial in determining potential violations of title VI and title IX in the context of clinical trials and health research.

Finding: The NIH grant application states that research involving human subjects must comply with NIH guidelines on the inclusion of women and minorities in clinical trials. A clear and compelling rationale and justification for not including minorities and women must establish that inclusion is inappropriate with respect to the health of the subjects or the purposes of the research. Cost and childbearing potential are not acceptable reasons for exclusion. Application instructions state that grantees must report annual enrollment of women and men and the race and ethnicity of research participants. But, it is unclear whether the reports are used to review compliance of individual grantees.¹⁷⁴

Recommendation: OCR, with the assistance of NIH, should develop a mechanism for reviewing grantees' annual reports on the inclusion of women and minorities as participants in federally funded research. Such information should be used as a preliminary review of the compliance of individual grantees.

In addition to reviewing such reports, OCR should develop a mechanism by which OCR monitors whether researchers are including women and minorities in adequate numbers in their research. For example, OCR could accomplish this through visits to research sites or reviewing researchers' documents and records on clinical trial participants. OCR also should establish guidelines on the inclusion of women and minorities in health research. Such guidelines should incorporate the guidelines already pre-

pared by NIH and other operating divisions, and should be written in an easy-to-use format that provides specific examples and clearly describes OCR's policy on the inclusion of women and minorities in clinical trials.

Health Care Financing Administration

Finding: HCFA's monitoring of equal access to health care is impaired by its data collection system and the information on beneficiaries' race and ethnicity recorded in it. HCFA does not have definitive information on the race or ethnicity of every beneficiary. Because the medicaid program is a Federal/State program, the operating division concluded that it could not require States to make changes to the race/ethnicity field in their data systems. At the same time, HCFA also does not have complete information on the race or ethnicity of all medicare claimants. HCFA staff recently made an effort to identify the race/ethnicity of medicare beneficiaries but did not eliminate the problem.¹⁷⁵

Recommendation: HCFA must continue to pursue getting more complete information on the race and ethnicity of medicaid and medicare beneficiaries so that the access to care of minorities and women can be tracked. OCR should provide guidance to and work jointly with HCFA to ensure appropriate data are collected. For example, in addition to data on race, ethnicity, and gender, HCFA should maintain information on the types of medical services received, quality of care, etc.

Finding: A HCFA manual provides recipients guidance on producing materials reaching out to beneficiaries. It gives standard language about discrimination to be included in publications. The manual also addresses writing for audiences with low literacy, cultural differences, and cultural sensitivities. However, the guide does not make any suggestions for outreach to persons for whom English is a second language, for example, whether bilingual materials should be provided, or if an interpreter should be made available.¹⁷⁶

Recommendation: HCFA's outreach manual should be revised to include information on reaching persons for whom English is a second language and other persons with linguistic bar-

¹⁷³ See chap. 5, pp. 245-48.

¹⁷⁴ See chap. 5, pp. 245-48.

¹⁷⁵ See chap. 5, pp. 251-52.

¹⁷⁶ See chap. 5, pp. 252-53.

riers. The guidance should be based on OCR's guidance on limited English proficiency and should be coordinated through OCR.

Finding: Among the operating divisions, HCFA has the most interaction with OCR. However, the extent to which HCFA performs external civil rights functions remains unclear, due in part to the lack of clarity not just in HCFA's role as an agency but with respect to the roles of individual HCFA staff members. On the surface, it appears that the focus on internal civil rights enforcement prevails within HCFA. The functions and activities of HCFA's Office of Equal Opportunity and Civil Rights (OEOCR) appear to revolve around equal opportunity and internal civil rights activities rather than external civil rights issues. OEOCR's director explained that "Civil Rights" had been added to the name of the office in 1997.

HHS/OCR has delegated more authority for civil rights enforcement activities to HCFA than any other operating division. Nonetheless, HCFA's OEOCR has only 18 staff members. They include a director, an administrative officer, and a secretary; the rest are EEO managers, EEO specialists, or EEO assistants. However, only three of these staff are assigned to extramural civil rights matters—one EEO manager and two EEO specialists.

Although the MOU *could* be sufficient as a means of authorizing HCFA to conduct external civil rights enforcement efforts, the two agencies have not worked together to implement it so that all confusion would be removed as to the *exact nature* of HCFA's role, particularly whether or to what extent this role encompasses external civil rights enforcement. It appears the main problems are the clarity with which the instrument delegating authority delineates HCFA's role and both agencies' coordination and implementation efforts, particularly in fashioning clearly their objectives in involving HCFA in any external civil rights enforcement efforts and their ability to execute those external civil rights matters.¹⁷⁷

Recommendation: The Secretary of HHS should clarify HCFA's delegation of civil rights authority with respect to HCFA's legislation or through regulations. Alternatively, OCR's delegation of authority should be rewritten to clarify HCFA's role, to the extent that OCR wishes it to

have a role, in supporting OCR's external civil rights enforcement efforts. Moreover, the two agencies should work closely together to implement the delegation of authority so that all confusion is removed as to the *exact nature* of HCFA's role, particularly whether or to what extent this role encompasses external civil rights enforcement. Specifically, the Secretary of HHS should strongly indicate that all final decisions on external civil rights matters must be approved by OCR.

Administration on Aging

Finding: The Administration on Aging (AoA) demonstrated a lack of understanding of its extramural civil rights responsibilities. AoA indicated that the enforcement of nondiscrimination laws regarding access to health-care for women and members of racial and ethnic minority groups is irrelevant given AoA's mission. The Assistant Secretary for Aging failed to recognize that the operating division must promote civil rights compliance in health services it supports indirectly through its funding recipients. The operating division administers several special programs for the aging through State grants and is responsible for supporting OCR's enforcement endeavors through whatever activities OCR deems appropriate, typically outreach and technical assistance.¹⁷⁸

Recommendation: The AoA's lack of understanding of extramural civil rights responsibilities demonstrates that OCR needs to train the operating division on its responsibilities. In its training OCR must distinguish between the traditional enforcement activities, that is, complaints investigations and compliance reviews, that it has reserved for itself, and broader extramural activities that are the responsibility of the operating division. These activities include ensuring that applicants receive appropriate civil rights assurance forms to submit and promoting civil rights compliance among funding recipients through activities such as outreach, technical assistance, or whatever else OCR deems appropriate.

Indian Health Service

Finding: The Indian Health Service (IHS) demonstrated a lack of understanding of their

¹⁷⁷ See chap. 5, pp. 240–42.

¹⁷⁸ See chap. 5, p. 236.

extramural civil rights responsibilities and had no knowledge of OCR guidance pertaining to them. Yet extramural civil rights issues are clearly important in the operating division. IHS provided correspondence concerning suspected patterns of discrimination against Native Americans and Alaskan Natives involving State and local programs or State and local administrations of federally funded programs. An IHS memorandum of agreement with OCR clearly identifies IHS' responsibilities to notify OCR of instances of discrimination and to enforce program requirements with IHS contractors who deny services to their Native American and Alaskan Native clients. Several IHS grant application kits, like those other operating divisions use, require the applicant to sign an assurance of compliance with Federal statutes relating to nondiscrimination, thus invoking the mechanism by which all recipients of Federal assistance are accountable for civil rights compliance.¹⁷⁹

Recommendation: OCR needs to train IHS on its civil rights responsibilities. Training should cover all responsibilities delegated to IHS through an MOU or other delegated agreement with OCR. OCR should provide technical assistance to IHS on civil rights statutes and the role of complaints investigations and compliance reviews. OCR should also instruct IHS staff on issues concerning civil rights assurance forms and promoting civil rights compliance among funding recipients through activities such as outreach, education, and technical assistance.

Finding: IHS has been concerned that Native Americans or Alaska Natives are eligible for all health care services or payments for services that other persons are eligible for, yet they are often refused such services and referred to IHS services, which are intended to provide only residual medical care and services. IHS has had a three-party agreement involving IHS, OCR, and HCFA, to address the civil rights enforcement of this issue since 1974.

The agreement lists the responsibilities of OCR, HCFA, and IHS to implement this policy. OCR must designate headquarters and regional staff to serve as liaisons with IHS for civil rights complaints and activities related to the agreement. It must collect sufficient information from State and local agencies and medical service

providers to monitor civil rights compliance. It must investigate any complaints or information IHS forwards regarding complaints of this type of discrimination and proceed with other appropriate enforcement activities. Finally, it must require State and local agencies that administer medical service programs to communicate the availability of services to American Indian or Alaska Native communities.

The agreement requires IHS to coordinate outreach with other groups and organizations to inform Native Americans and Alaskan Natives about their eligibility for health services payment programs. IHS also is required to assist Native Americans and Alaskan Natives with obtaining the necessary certifications for these programs and in filing complaints with OCR. IHS must enforce requirements of contractors concerning third-party payment for services rendered to eligible Native Americans and Alaskan Natives and notify OCR of instances of health care providers' or contractors' noncompliance. Further, the agreement stipulates that IHS must help identify the number of Native Americans and Alaska Natives eligible for various federally assisted services so that service to them can be monitored. The agreement states that HCFA must inform State agencies administering the medicaid program about the policy on the eligibility of Native Americans and Alaskan Natives, ensure that State plans and practices do not conflict with this policy, provide technical assistance to develop procedures to avoid non-compliance, and notify OCR of instances where State or local agencies deny Native Americans or Alaskan Natives eligibility in noncompliance with the policy.¹⁸⁰

The three-party agreement is clear about what responsibilities each party bears. It clarifies IHS and HCFA responsibilities for extramural civil rights activities, yet does not delegate any authority for conducting complaints investigations or compliance reviews. Thus, it does not extend the operating division's responsibilities any further. Similarly, OCR's responsibilities, apart from providing headquarters and regional liaisons, are nothing more than the enforcement activities for which they are responsible even in the absence of an agreement.

¹⁷⁹ See chap. 5, pp. 236–37.

¹⁸⁰ See chap. 5, pp. 242–43.

The three-party agreement does not, however, appear to have overcome discrimination against Native Americans and Alaskan Natives in health service payment programs. In a 1994 memorandum, IHS concluded that OCR was not enforcing civil rights with respect to Native Americans. It noted first that the agreement was a compromise—IHS wanted OCR to establish an “Indian Desk” rather than liaisons. Second, OCR does not give American Indian and Alaskan Native issues a high priority. Third, OCR fails to recognize incidents of apparent discrimination against Native Americans and Alaskan Natives as indicative of statewide, institutionalized discriminatory attitudes, policies, and procedures.

Recommendation: OCR, IHS, and HCFA must each carry out the tasks agreed to in the three-party agreement. OCR must designate headquarters and regional staff to serve as liaisons with IHS for civil rights complaints and activities related to the agreement. It must collect sufficient information from State and local agencies and medical service providers to monitor civil rights compliance. It must investigate any complaints or information IHS forwards regarding complaints of this type of discrimination and proceed with other appropriate enforcement activities. Finally, it must require State and local agencies that administer medical service programs to communicate the availability of services to American Indian or Alaska Native communities.

IHS must coordinate outreach with other groups and organizations to inform Native Americans and Alaskan Natives about their eligibility for health services payment programs. It must assist Native Americans and Alaskan Natives with obtaining the necessary certifications for these programs and in filing complaints with OCR. IHS must enforce requirements of contractors concerning third-party payment for services rendered to eligible Native Americans and Alaskan Natives and notify OCR of instances of health care providers’ or contractors’ noncompliance. IHS must also help identify the number of Native Americans and Alaskan Natives eligible for various federally assisted services so that service to them can be monitored.

HCFA must inform State agencies administering the medicaid program about the policy on the eligibility of Native Americans and Alaskan Natives, ensure that State plans and practices

do not conflict with this policy; provide technical assistance to develop procedures to avoid non-compliance, and notify OCR of instances where State or local agencies deny Native Americans or Alaskan Natives eligibility in noncompliance with the policy.

Furthermore, OCR must meet with IHS to design a system to monitor contractors’ third-party payment services rendered to Native Americans and Alaskan Natives. The system should make use of any information IHS has collected on the numbers of eligible Native Americans and Alaskan Natives to determine how extensively services are denied to these groups. OCR should help identify any additional information IHS might collect to monitor this issue and grant them the authority to collect this information. The information should be collected in sufficient detail to determine whether State policies are having adverse effects on these groups. OCR should immediately undertake compliance reviews of medicaid providers to determine whether State policies or practices are failing to provide the third-party payments for which Native Americans and Alaskan Natives are eligible.

Chapter 6. Health Care Reform

Ensuring equal access to quality health care and nondiscrimination in the distribution of health care services for women and minorities has become an important part of a larger national goal. The demographic composition is rapidly changing as “minority” populations continue to grow. The health care system needs to address the delivery of services to the growing and diversifying racial/ethnic minority populations, particularly those for whom English is not a primary language. HHS has recognized these disparities in health status and access to health care as a nationwide problem. Despite efforts of HHS and other Federal, State, and local agencies, disparities in health status and health care delivery continue to exist, and therefore require examination from a civil rights perspective.

Overall, efforts to reform health care policy in the 1990s have created a heated debate among policymakers as to the most effective plan of action and the goals that health care reform should strive to accomplish. Economic proposals for reforming health care and attempting to improve access based on the premise that the primary

barrier to care is socioeconomic may neglect to address the racial/ethnic backgrounds of participants and discrimination as barriers to health care. Although health care reform that focuses exclusively on socioeconomic factors can improve access, ensuring universal health care coverage that reflects the principles of equal access and nondiscrimination and provides quality service to everyone requires a health care reform policy with strong mechanisms for removing other discriminatory barriers.

Policymakers have recently tried to address these issues through legislation which, although well-intentioned, fails to address adequately the breadth of inequalities. For example, the proposed 1999 Patients' Bill of Rights included protections for patients, but was limited to group health plans and health insurance issuers, and not health care providers and facilities. New legislation should be comprehensive—that is, applicable to the entire system of health care delivery.

Any new legislation should address cultural and linguistic barriers to health care as well as racial and ethnic diversities. For example, Congress should include a provision requiring interpreter services, translation of medical records, and provision of informative brochures and documents in multiple languages. In addition, gender competency should be included as a provision in new legislation. The health needs of women, beyond those that are related to reproductive health, must be emphasized. Moreover, medical educators and providers must be made aware of the effects of cultural and gender differences on health care.

Any comprehensive efforts to reform the health care system must focus attention on dismantling *all* barriers that women and minorities confront in obtaining equal access to quality diagnostic, preventive, and primary health care. Civil rights provisions should be an integral part of health care reform policy, and are necessary because they are the best hope for reducing the significant barriers to preventive health care and health treatment. Thus, a second reform measure must be designed to address the ability to pay for health care as a barrier to accessing the highest quality medical treatment. Proposed initiatives to ensure “universal access” to health care must give deliberate attention to the “most disadvantaged economically,” especially due to their higher rates of disease and disability. Ad-

vancing the ability to access health care for low-income populations will ultimately improve the health of the Nation.

The Need for Civil Rights Provisions in Health Care Reform Packages

Finding: Evidence presented thus far has demonstrated the degree to which racial, ethnic, and gender disparities in health care access, delivery, financing, and research exist. It is crucial that Congress, the President, and HHS take action to eliminate the disparities. Yet there are differing views on the most effective way of doing so, particularly in the policy arena. Several bills to reform health care have been proposed, none of which have focused on both the economic barriers to care *and* discriminatory policies and practices that prevent access.¹⁸¹

Recommendation: One of the primary focuses of “health care reform” must be on civil rights and the right to equal access to quality health care. Any comprehensive efforts to reform the health care system must focus attention on dismantling all barriers, including both economic and noneconomic obstacles, that women and minorities confront in obtaining equal access to quality diagnostic, preventive, and primary health care. As such, civil rights provisions should be an integral part of any health care reform policy. Health care reform must ensure that racial/ethnic minorities and women have equal access to health care providers and facilities; that they receive the same high quality level of services, procedures, and treatment protocol for any given set of symptoms or conditions; and, finally, that there is no form of discrimination as defined in existing Federal civil rights statutes and regulations, including on the basis of economic status. The means for addressing these concerns must be embedded in civil rights legislation intended to strengthen and expand upon the civil rights provisions offered by non-discrimination statutes in the health care context. Accomplishing equal access to services in general as well as to the same quality care will require multiple pieces of legislation.

¹⁸¹ See generally USSCR, *The Health Care Challenge*, vol. I, and chap. 6, pp. 263–64.

Ensuring Access to Quality Care

Finding: Proposals for reforming health care that are based solely on economic reform neglect to address other barriers to quality health care, most significantly discriminatory practices based on race, ethnicity and gender. Federal health policymakers must acknowledge that “universal coverage,” although critical, does not automatically ensure that racial, ethnic, and gender inequities and economic discrimination are eliminated. Persistent restrictive admission practices, racial, cultural, and gender stereotypes, and the failure to employ minority health professionals all continue to pervade health care delivery, and contribute to impeding minorities’ and women’s access to the health care system. While such barriers are intimately related to economic status, they go beyond the ability to pay for care. Ensuring universal health coverage that truly reflects the principles of equality of access and nondiscrimination requires a health reform policy that includes strong mechanisms for removing other barriers for racial/ethnic minorities and women.¹⁸²

Legislation attempts proposed to date have been missing the crucial element of a nondiscrimination provision, including sufficient strategies to remedy gaps in access to care and the provision of services and ensure that health care is delivered effectively. Further, they do not appropriately incorporate standards for ensuring that all patients’ needs are met, and that specific needs of women and racial and ethnic minorities are incorporated into the basic operations of health care delivery. For example, the versions of the Patients’ Bill of Rights proposed in 1999 included many necessary elements; however, they failed to address the need for gender, cultural, and language competency—needs that are critical to the provision of quality health care. Specifically, the 1999 proposed Patients’ Bill of Rights did not address the role gender plays in nongynecological health issues, from the types and prevalence of diseases women experience, to the differences in symptoms and types of treatments that are most appropriate for women. It also did not ensure equitable, nondiscriminatory treatment by health care providers or that they deliver “culturally competent” care. Further it did not consider that language minority indi-

viduals are denied “meaningful access” to health care if they are not provided with assistance in communicating with their doctors.¹⁸³

Recommendation: There is a dire need for legislation that will ensure that women and minorities are afforded equal access to quality health care. Such legislation must go beyond mere rhetoric to eliminate facially neutral practices and policies that have an adverse impact on underserved groups. New legislation must make a firm commitment to comprehensively define and enforce civil rights in the health care context and must be in touch with the needs of an increasingly diversified Nation and an ever changing health system.

In order to be comprehensive, legislation should incorporate a number of provisions that would not only ensure the competency of health care providers, but will significantly improve the quality of care provided:

Gender Competency. A new proposal should have a requirement that board-certified physicians have a comprehensive understanding of the distinctions in male and female physiology, health behaviors, and health risks. They should stipulate that board-certified physicians’ medical education must include training in the unique health care needs of women beyond their reproductive health, and acknowledge the underlying biological factors that contribute to gender differences in the causes and prevention of particular diseases, and differences in appropriate treatment modalities. Such a bill should also encourage and provide funding to conduct research on gender-specific issues related to health care, as well as to encourage women to pursue careers in areas of medicine that have traditionally not been occupied by women, such as research. Similarly, reform statutes should appropriate Federal funds to train current practitioners and administrators in providing care that considers gender distinctions.

Cultural Competency. A new proposal should require the inclusion of model “cultural competency programs” in all health care programs. Cultural competency programs must aim to reduce the cultural and communication barriers that racial/ethnic minorities face in attempting to access and participate in the Nation’s health care delivery system. For instance, the statute

¹⁸² See generally chap. 6.

¹⁸³ See chap. 6, pp. 264–70.

should require the promulgation of HHS guidelines recommending that State and local governments develop task forces composed of policymakers, health care providers and administrators, community advocates, and scholars to facilitate the delivery of culturally and linguistically competent and sensitive health care services.

HHS guidelines should require these task forces to develop plans providing for outreach, education, and the dissemination of information on influences of culture and language in access to and quality of health care. The plans also should include training programs for all health care professionals on the need to appreciate and understand the operation and effect of cultural and linguistic differences on their patients' ability to access quality health care. This training should include guidance on working with language interpreters; becoming more aware of cultural differences among different racial/ethnic groups; and incorporating this knowledge into interactions with minority patients. The task forces also should ensure ways to keep Federal, State, and local agencies informed of the effect of population changes, such as of language minority groups on health care delivery systems.

The plan should further stipulate that, in order to receive a medical license, primary and specialty care physicians must complete course work, as a standard part of their medical training, to develop "cultural competency" and sensitivity to various ethnic groups' health behaviors, health risks, customs, attitudes about seeking care and following a prescribed treatment protocol, and expectations of medical care. A companion program statute should be implemented that appropriates Federal funds so that health practitioners and administrators are trained to better understand diverse ethnic groups, and to thereby provide more culturally sensitive care.

Language Competency. Facilities and providers should be required to take all appropriate steps to ensure equal access to quality health care for language minority individuals. Such steps should include interpreter services to assist language minority patients/clients in communicating with providers and conveying their needs during office and hospital visits. Health care reform legislation should require that the individuals charged with translating languages are fluent in both English and the patient's primary language, have at least some familiarity

with medical terms, and be willing to keep the health care provider-patient interactions confidential. Further, health care providers should be required to provide translations of personal medical information and records from office visits and general health care information. The only exception to this obligation should be in cases where obtaining interpreter services would result in a threat to the patient's life, as in emergency situations.

Finding: Another element conspicuously missing from legislation in its current form is a comprehensive nondiscrimination provision. The proposed 1999 Patients' Bill of Rights contained a brief nondiscrimination provision that prohibited health care plans from discriminating against enrollees, beneficiaries, and participants in relation to health care coverage and in the delivery of health care services consistent with the benefits covered under each individual's selected health plan. However, the precise language of this nondiscrimination provision indicated that it was limited in application to group health plans and health insurance issuers and does not explicitly apply to health care providers or facilities.¹⁸⁴

Recommendation: Any new legislation should ensure that hospitals, health maintenance organizations, nursing homes, physicians, and any other systems of care are required to incorporate, as part of their quality assurance protocols, an ongoing mechanism to monitor and assess any racial and gender disparities in treatment. Health care facilities should be required to establish an auditing review board or task force to track disparities occurring in patients' use of services and in the choices of diagnostic and therapeutic alternatives offered to patients.

Congress should require the promulgation of HHS guidelines giving HHS responsibility for implementing such review boards. These guidelines should explain that the main function of these boards is to determine the following: (a) the choices nonminority and minority (and female versus male) patients are offered by their physicians, (b) the criteria used by physicians in making clinical judgments, and if such standards are applied equitably across all ethnic groups and both genders, and (c) the extent to which decisions for all patients, male or female

¹⁸⁴ See chap. 6, pp. 266-70.

and from all ethnic groups, are based strictly on medical need.

The HHS guidelines should include at least the following procedures:

- Compare the racial/ethnic composition of the area surrounding the health care facility or provider (using census data, for instance) with the racial/ethnic composition of individuals obtaining services at the facility or with a provider, and determine if any significant disparities exist. A disparity would reveal that a particular racial/ethnic group is receiving a disproportionate level of access to care.
- Determine if women and men receive the same (or “gender equivalent”) procedures and same overall quality of care (holding all other factors constant) when they present a similar condition, disease severity level, or set of symptoms. A similar comparison would be performed between each major racial/ethnic minority group and whites with similar health status.
- Determine if any gender or racial/ethnic disparities occur with respect to admissions to health care facilities (e.g., hospitals, nursing homes, HMOs, rehabilitation centers, public health clinics, other outpatient care centers, home health agencies), visits to physicians and other health care providers, and the quantity and quality of specific services (e.g., diagnostic, preventive, rehabilitative, primary/ambulatory care, mental health, therapeutic) and procedures (e.g., laboratory tests, x-rays, including MRI and mammography, dialysis, surgeries, organ transplants, amputations) performed.

Further, Congress must acknowledge the importance of civil rights *enforcement* to determine the manner and consistency with which health care providers are incorporating the mandated efforts into their daily operations. This monitoring falls under the jurisdiction of OCR, therefore, legislation should require OCR to conduct pre- and postaward compliance reviews of all health care facilities that receive HHS funds. Further, proposed legislation must *explicitly* state that OCR is responsible for ensuring compliance with all civil rights statutes applicable to health care programs, particularly title VI and title IX. The legislation must require OCR to de-

velop a strong enforcement plan, including the provision of technical assistance. Further, health care facilities must be required to provide information to beneficiaries that explains the role of OCR and how to file a discrimination complaint with OCR.

OCR should play a central role in any legislation addressing access to health care. OCR must be directed to review any policies or programs resulting from health care reform efforts. The Secretary of HHS, with OCR’s guidance, also should play an active role in crafting health care reform legislation. The Secretary must ensure that all individuals have access to appropriate, high-quality health care services and insurance, regardless of their race, color, ethnicity/national origin (including English proficiency level), sex, religion, age, mental or physical disability (including HIV status), sexual orientation, genetic background, geographic location of residence, ability to pay, or any other factor unrelated to the need for medical care.

Finding: The prevalence of adverse impact discrimination against minorities in the health care industry indicates the need to develop appropriate standards for determining civil rights compliance by health care practitioners and facilities, and for determining if particular health care practices have an adverse impact on minorities and women. Such adverse impacts operate to exclude a disproportionately large number of minority Americans and women from access to health care and result in a lesser quality and quantity of treatment for these population groups than for others. Determining the presence of this form of discrimination requires well-defined standards and criteria for assessing the extent to which a given health care facility’s or provider’s policies are the cause of the disparate or adverse impact against women and minorities.¹⁸⁵

Recommendation: In enacting Federal health care reform, Congress should provide enforceable standards to ensure a maximum level of quality and consumer protections for all health care consumers. Congress should require health care facilities or providers to show through empirical evidence that a policy or practice that has a disproportionate impact on members of minority groups and/or women is essential to the provision of quality, accessible health

¹⁸⁵ See chap. 6, pp. 269–70.

services, and significantly furthers an important, legitimate purpose that cannot be substantially accomplished or achieved through less discriminatory means.

For example, Congress should identify the following practices as potentially discriminatory: admitting patients to hospitals only if they have a treating physician with staffing privileges; requiring patients to provide a substantial financial deposit in order to be treated for emergency services or inpatient care; failing to provide accessible interpreters; neglecting to translate signs and forms; making preadmission inquiries into patients' citizenship, national origin, or immigration status; refusing to deliver babies from mothers who have not received a minimal amount of prenatal care; denying or limiting care to medicaid patients; and establishing or reestablishing facility locations so that minority communities face difficulties in accessing health care.

Health care providers should be required to identify, assess, and accept less discriminatory alternatives, even if they are more "burdensome" or costly, as long as the difference is not too substantial and the health-related objectives of the disparately impacting policy are virtually achieved. This assessment is crucial in determining the necessity of a policy and whether there are alternatives that would reduce or eliminate a disparate racial or gender impact. Important objectives for making such an assessment in the health care context can include maintaining a high-quality medical program or acting in the interest of patient and staff safety. In contrast, a mere interest in cutting costs or saving money, without some element of financial necessity, would not qualify as an "important interest."

Further, a health care provider who is administering care that has a disproportionate impact on minorities or women should be required to show that a challenged policy "significantly furthers" rather than merely "serves" an important purpose. The health care provider should have empirical evidence to substantiate that practices in question substantially further an important program goal.

A health care reform statute should explicitly state that it is the provider's responsibility to substantiate that there is no alternate medically effective or feasible approved procedure to perform on the individual filing the claim, when a

certain health care practice is challenged. Because the burden of justification rests on recipients, they should be accorded an opportunity to have an OCR finding of violation reviewed by an independent body. The Secretary of HHS should issue a delegation of authority to the Assistant Secretary for Planning and Evaluation to create an independent advisory body in the form of a review board. HHS should develop guidelines for the review board to evaluate OCR determinations. This review board should include medical doctors, research scientists, health care and civil rights advocates, and individuals representing business interests. The guidelines should empower both OCR and recipients to request that the review board convene to determine whether the recipient's justification has met the appropriate compliance standard. If the board determines that there is a less discriminatory alternative to the recipient's practice, the review board should participate in the development of methods to implement the alternative. Decisions of the review board are advisory in nature. OCR would not be bound by these decisions.

Finding: Although the 1999 proposed Patients' Bill of Rights included a requirement for health care and insurance plans to collect data in a standardized format, the bills did not specify the types of demographic information that must be collected, nor the frequency of data collection. Further, there was no requirement for Federal, State, and/or local health care agencies to systematically collect or report data by race, ethnicity, or gender for the purposes of determining discrimination in health care service utilization.¹⁸⁶

Recommendation: Any attempt at health care reform must require the systematic collection and analysis of data on access to health care and utilization of health care services, procedures, and treatments, by race/ethnicity and gender. Analysis and dissemination of such information is the optimal way to identify patterns and barriers that have a disproportionate adverse impact on health care for women and minorities. On a regular basis, HHS and State and local health care agencies should collect, aggregate, and analyze data on gender and racial/ethnic background in conjunction with patients' health status and the particular diagnostic, preventive, rehabilitative, therapeutic, pri-

¹⁸⁶ See chap. 6, pp. 269–70.

mary/ambulatory care, mental health, and other needed services, and specific procedures and treatments delivered.

HHS should work with all health care providers and facilities that receive Federal funds to develop a uniform computerized system of data collection. On a quarterly basis, State and local health care agencies should collect data from all health care providers and facilities concerning medical transactions during that quarter. Such data should be submitted to the appropriate State health care agency which should synthesize and analyze the data. Each State agency also should forward the quarterly data report to HHS. HHS then should assess each State's quarterly report; synthesize and document the findings on racial/ethnic and gender disparities in access to health care services and specific procedures; and report on the extent to which the Nation is progressing in closing racial/ethnic and gender gaps in health status, access to providers, and utilization of health care services, and ensuring overall equity and nondiscrimination in the health care arena. HHS should provide an annual summary of the findings of these analyses to Congress and the President.

In addition, Federal, State, or local agencies should provide guidance and technical assistance to health care practitioners and facilities with respect to appropriate strategies to collect, compile, and submit race and gender data from each medical transaction. All data collection mechanisms should be compatible to ensure ease of transferring data to government agencies.

Building on Existing Law to Expand Civil Rights Accountability

Finding: There are significant limitations in the scope and/or coverage of present civil rights laws that undercut the ability of present laws to reach *all* individuals in the health care system. For instance, title VI of the Civil Rights Act of 1964 protects against discrimination in only federally assisted programs. Similarly, protection under Hill-Burton, while covering several classifications, applies only to facilities that received funds under the Hill-Burton program.

In addition, much of existing civil rights law applicable in the health care context only proscribes certain action but does not require proactive efforts on the part of covered entities to remain in compliance with its mandates. However,

in civil rights laws applicable in other contexts, Congress has indicated the need for covered entities to engage in proactive steps to overcome discrimination. For example, under the Equal Educational Opportunities Act of 1974 (EEOA), school districts are prohibited from denying equal educational opportunity, which implies that covered entities must take *proactive* steps to remain in compliance with the law.¹⁸⁷

Recommendation: New, comprehensive civil rights legislation must build on and broaden the scope of existing civil rights law. For example, in order to cover *all* providers, civil rights legislation relating to health care should derive its authority under the Constitution from the commerce clause so that it can reach all health care providers "affecting commerce," rather than being limited to only those providers receiving Federal funds. In expanding the coverage of title VI and Hill-Burton, new civil rights legislation in the health care setting should widen its scope first by incorporating additional protected classifications, including race, color, national origin (including English proficiency level), sex, religion, age, mental or physical disability (including HIV status), sexual orientation, genetic background, geographic location of residence, ability to pay for care, or any other factor unrelated to the need for medical care.

In addition, under new, expanded civil rights legislation, all health care providers and facilities would have an affirmative duty to take appropriate action to assist patients in overcoming language and cultural barriers that can hinder their access to health care services. Analogous to the Equal Educational Opportunities Act, the new legislation should state that health care providers' failure to take appropriate action to overcome the language and cultural barriers that impede equal participation in health care services amounts to a denial of access to quality health care. Extrapolating from the EEOA's mandate, the central objective should be to ensure the provision of equal access to quality health care.

Overall, this new expanded civil rights legislation should provide a Federal statutory underpinning for civil rights protection through a proactive and remedial approach. The focus of this new legislation would be ensuring equal access

¹⁸⁷ See chap. 6, pp. 271-73.

to high quality health care in all programs as a means of remedying past civil rights violations while preventing the emergence of new ones. This legislation should reflect the Nation's commitment to ensuring that the highest quality health care services are made accessible to all individuals.

A new civil rights statute built on and expanding existing civil rights legislation should include the following among its key provisions:

- No individual health care provider or practitioner¹⁸⁸ or facility¹⁸⁹ shall deny an individual equal access to quality health care, including any type of health care service;¹⁹⁰ specific procedure;¹⁹¹ or other form of treatment, according to accepted principles and standards of professional medical practice, on the basis of race, color, national origin (including English proficiency level), sex, religion, age, mental or physical disability (including HIV status), sexual orientation, genetic background, geographic location of residence, method of payment, or any other factor unrelated to the need for medical care.
- No individual health care provider or practitioner, group of providers, or facility shall deny an individual equal access to a particular service, procedure, or treatment protocol by the failure to take affirmative steps and appropriate action to overcome language barriers that impede equal participation by patients, clients, and prospective beneficiaries in the entire array of health care programs and services, and to overcome other barriers that obstruct the progress of individuals with limited English proficiency in maintaining and improving their health status.

¹⁸⁸ "Individual health care provider/practitioner" is defined as including but not limited to, primary or specialty care physician, osteopath, nurse, mental health counselor, dentist, pharmacist, other clinician, or group of providers.

¹⁸⁹ "Facility" is defined as including, but not limited to, hospital, health maintenance organization, nursing home, home health agency, rehabilitation center, and outpatient clinic.

¹⁹⁰ "Health care service" is defined as including, but not limited to, diagnostic, preventive, primary/ambulatory, rehabilitative, therapeutic, and mental health.

¹⁹¹ "Specific procedure" is defined as including, but not limited to, routine disease screenings such as laboratory tests, x-rays, including MRI and mammography, dialysis, surgeries, organ transplants, and amputations.

A Final Recommendation: The recommendations presented thus far were designed to offer assistance to OCR in more effectively carrying out its civil rights enforcement responsibilities and activities within the current structural and fiscal constraints of HHS. However, for civil rights enforcement to be most thoroughly ingrained in the current health care system, Congress should create a new agency in the form of an independent commission to implement and enforce the new civil rights statute recommended above. The new agency should absorb OCR and all its enforcement functions and should establish 10 regional offices across the country and field offices as appropriate, particularly in remote rural communities.

Congress should require the new agency to develop an enforcement scheme for the new statute as well as the older civil rights statutes already enforced by OCR. As part of this enforcement scheme, the agency should be required to issue general guidelines within 2 years of the statute's passage. Specifically, this agency should be responsible for developing protocols and standards to more thoroughly define equal access and quality of care. The agency should be staffed with civil rights analysts, investigators and attorneys, health science administrators, medical doctors, research scientists, individuals with civil rights advocacy backgrounds, individuals with economics and sociology training, and individuals with expertise in finance.

The agency, as an independent commission, will make determinations in cases alleging the denial of equal access to quality health care under the statute. The commission would have the authority to determine whether or not a health care service provider denied equal access to quality care or engaged in other unlawful discrimination in a given case. The commission would base its decisions on guidelines developed by the agency. In addition, the new agency should develop technical assistance and a complaints processing scheme for this statute as well as the other statutes it enforces.

Effective enforcement of the new statute will require this agency to focus on the following six areas to fully realize the objectives of the new statute as well as those of the other civil rights laws it will enforce. These six areas are: compliance, enforcement, and litigation support; policy and procedure development; coordination and

assistance for Federal, State, and local governments; civil rights training; public education and outreach; and data and systems analysis. To conduct each of these activities effectively, the new agency should be divided into the following six units, each devoted to specific civil rights functions and each with sufficient staff and resources to accomplish their tasks:

Compliance, Litigation, and Enforcement: This unit should be responsible primarily for reviewing and assessing agency enforcement actions and referrals. Specifically, this unit will be responsible for conducting preaward reviews, postaward desk-audit reviews, compliance reviews, complaint investigations, and data collection. This unit should review all agency letters of finding and Federal funding suspension, deferral, and termination decisions to ensure accurate and consistent enforcement of civil rights statutes within the agency's jurisdiction. This unit should receive all agency referrals for litigation. However, the unit should seek assistance from specific program subunits responsible for specific statutes. Each statute for which the agency has enforcement responsibility should have a separate subunit that deals with only one statute. Each subunit should be staffed with health science administrators, medical researchers, health care policy analysts, attorney-advisors, civil rights analysts, and equal opportunity specialists and investigators all with title VI expertise.

Policy and Procedure Development: This unit should serve as the central office for the development and dissemination of all policies and procedures. This unit should develop and revise regulations, guidelines, policies, and compliance manuals for use by the agency's various units, State and local government recipients, nongovernmental recipients, applicants, beneficiaries, and the general public. In addition, this unit should work with the Planning, Analysis, and Systems Services unit and the Federal, State, and Local Government Coordination Unit to design a new civil rights enforcement plan that should supersede and improve on the current civil rights implementation plan. This unit should define the procedures and terms necessary for developing an agency civil rights enforcement plan, such as preaward reviews, postaward desk-audit reviews, compliance reviews, complaint investigations, and data collection. It is essential for this unit to consult with

all other units and Federal agencies to develop policies and procedures that serve the needs of civil rights compliance and enforcement practitioners.

This unit also should have primary responsibility for reviewing new legislation to assess their effect on civil rights. The unit should review not only legislation directly involving civil rights, but also provisions creating or affecting health care, including health care insurance, reform, clinical research trials, and Federal financial assistance programs. This unit should be staffed primarily with health care policy analysts, social scientists, attorney-advisors, civil rights analysts, and equal opportunity specialists.

Federal, State, and Local Government Coordination: This unit should be responsible for coordinating the implementation, compliance, and enforcement activities of the Federal agencies and State and local government health care recipients operating continuing programs or block grant programs on behalf of subrecipients. The unit's primary responsibilities should include the following: reviewing civil rights enforcement plans for approval or disapproval by the unit chief; facilitating and monitoring delegation agreements between agencies and between agencies and their subrecipients; providing technical assistance on request from government agencies and recipients; providing technical assistance proactively when the unit identifies deficiencies in an agency's plan or program; serving as a central clearinghouse for Federal, State, and local health care initiatives and programs; and working with agency program offices to facilitate and improve the collection of assurances from State and local government recipients.

This unit also should maintain a reference library and clearinghouse of HHS, other Federal agency, as well as its own strategic plans, policies, guidelines, and manuals to share with other agencies interested in developing their own materials. In addition, this unit should assist the other units by providing information on agency practices and the practical application of its regulations, policies, training programs, and public education and outreach activities. The unit's staff should consist of attorney-advisors, civil rights analysts, and equal opportunity specialists each assigned to specific agencies in order to develop expertise in the programs and operations of those agencies.

Civil Rights Training Center: The new agency should develop a state-of-the-art training program for educating staff on civil rights in health care. The training center should conduct training in all civil rights issues in health care for Federal, State, and local government agencies and medical schools and universities, health insurance companies, private health care providers, health care advocacy groups, members of the medical community, community and grassroots organizations, and the general public. The center should develop programs and materials to train individuals in a variety of issues and areas, such as the managed care industry, limited English proficiency, redlining, appropriate care, quality care, equal access, discriminatory impact, nursing home and home health care agency discrimination, organ transplantation, medical school admissions, grant application procedures, implementation and compliance procedures, and the development of methods of administration. The center should seek guidance from the other CORS units in order to target its training programs to address identified deficiencies.

The training center also should provide grants to organizations that conduct civil rights training in health care, such as medical schools and universities, hospitals, and health care advocacy groups. This will allow the training center to provide its participants with program-specific training presentations and materials. This unit's staff should comprise health science administrators, attorney-advisors, civil rights analysts, and equal opportunity specialists,

training specialists, and one employee development specialist to design programs for Federal employees to assist in career development.

Public Education and Outreach: This unit should develop, manage, and evaluate comprehensive public education and outreach programs to ensure public awareness and understanding of civil rights issues in health care. The unit should also establish and maintain relationships with organizations and associations concerned with civil rights in health care by using a variety of techniques and strategies to ensure an effective and mutually rewarding relationship health care stakeholders and customers. For example, the unit should participate in meetings and conferences, conduct onsite visits, and prepare and distribute brochures, pamphlets, handbooks, and exhibits. As a primary liaison between the agency, HHS, and its constituency, this unit should identify existing and emerging issues that are of concern to the community and communicate these issues to the other units. The unit should prepare materials on a variety of topics including, procedures for filing complaints under each of the civil rights statutes the agency enforces, the relationship between these statutes, and the effect of health care reform on civil rights. In addition, the unit should produce a publication, *Civil Rights in Health Care Forum*, on behalf of the agency with suggestions, articles, and materials from the other units and Federal agencies. This unit should be staffed primarily with health science administrators,

Statement of Chairperson Mary Frances Berry and Vice Chairperson Cruz Reynoso

As major changes unfold in the manner in which health care services are delivered and financed, this report provides a unique and valuable contribution to the national debate and focus on this issue. The report documents the vast disparities in access to quality health care among U.S. populations and calls for a major national commitment to identify and address the underlying causes of the disparity and the subsequent reconciliation of this health care crisis. The demographic changes that will occur in this country over the next decade magnify the importance of the report's findings and recommendations and the urgent need for cooperation among Federal, State, and local governments, as well as private organizations.

Recognizing the importance of health care as it relates to our success and productivity as a

nation, the Commission has consistently requested increases in funding for the U.S. Department of Health and Human Services' Office for Civil Rights. In furtherance of these requests, this report provides detailed information and guidance to OCR on crucial topics, such as closure of the health care financing gap, inclusion of people of color and women in health-related research, the acknowledgment of community-specific health needs, and the promotion of increased health care access for the underserved. The implementation of these recommendations will produce a meaningful improvement in the lives of many Americans who now disproportionately suffer from the burden of disease and disability.

Dissenting Statement by Commissioner Carl A. Anderson and Commissioner Russell G. Redenbaugh

The Commission's report on *The Health Care Challenge* is really two reports. First, it is an assessment of the enforcement of Federal laws by the U.S. Department of Health and Human Services (HHS) and its Office for Civil Rights (OCR). Second, it is an attempt to diagnose the chief ills of our health care system and to prescribe possible ways for addressing them. The report does a thorough job on the enforcement side of the issue; it clearly demonstrates the need for much-improved enforcement by HHS/OCR. The problem is on the prescriptive side, to the extent the report goes way beyond enforcement to advocate not only a whole new bureaucracy, but a national strategy to achieve a "leveling" in health care delivery, research, and financing. While we support much of what is in the report about the failures of Federal civil rights enforcement, the report is a thinly-veiled endorsement of universal health care, and advocates policies to achieve specific outcomes where market failures have not been demonstrated. That is why we decided, with reluctance, to vote against the report and that is the reason for this dissent.

Because the draft report we received is almost a thousand pages long, we cannot possibly address, in a brief dissent, all of our concerns. Some of the major problems we have identified include the following:

Invalid Assumption about the Nature of the Problem

Since the report was unable to prove "disparate treatment" (or "intentional discrimination"), it centers its discussion on the "disparate impact" theory, which is defined as "unintentional discrimination" that occurs "when a facially neutral policy operates in a way that affects a protected class of citizens disproportionately." The central theme is that everyone is entitled to the *same* "type, quantity, and quality" of health care services. The report considers "disparate impact" (for example, the fact that minorities may be less likely to have private insurance) to be the same as discrimination and, hence, remediable through civil rights legisla-

tion. This is a profound flaw. It will lead to more bureaucracy, more regulations and more wasted resources, but not "more health."

The Meaning of Health Disparities

The report is instructive in noting a number of disparities in areas such as life expectancy, mortality rates, disease prevalence rates, health care service utilization, availability of insurance, etc. These disparities are real, but their meaning is misinterpreted. For the most part they are a function of compromised access to care (reflecting private and public insurance coverage patterns) as well as lifestyle issues (e.g., drug use, sexual behavior, diet, smoking, etc.). Except in the obvious case of language barriers, they are not due to a lack of "cultural competence" or physicians' inability to communicate with patients of another race or ethnicity, nor is there evidence of physicians' failing to offer procedures to minorities because they are minorities.

The report tends to sweep away the problem of poverty and the impact it has on health care. Although the report (in volume I, chapter 2) does explain some of the socioeconomic factors influencing health care (education, income, and occupation), it fails to clearly identify the extent to which those factors (particularly poverty) explain differences in health care outcomes. In other words, is there a way to explain or identify health differences holding income constant? That is the important question the report has chosen not to address. The report concludes that since socioeconomic factors alone cannot account for all of the disparities, there must be "other factors" at work, i.e., discrimination and bias. Just to say that there may be "other factors" but that these are difficult to prove is not enough.

Cultural Competence

The "cultural competence" doctrine is a dangerous distraction from the real challenges we face with health care today. It is dangerous because it stresses identity politics over patient care and would substitute group-based generalizations for individual evaluations. It assumes that doctors (because of either a "conscious" or

“unconscious” bias) cannot communicate effectively with their patients who are “culturally different” or of another race and that this leads to fewer procedures which, in turn, leads to more illness among minorities.

There is no evidence, however, that race is a major determinant of how patients select their doctors, nor is there any reliable evidence or studies showing that anything but language compatibility really matters. It is true that doctors need to know a patient’s background and local practices of diet, home remedies, etc., as they affect the patient’s health, but doctors can do this with a relatively brief review of medical anthropology and by working with the patients themselves. In contrast, the measures outlined in this report would have doctors spend more energy separating patients into groups than treating them.

Nature of the Evidence

In going beyond civil rights to build a case for health care reform, the report relies heavily on law review articles and personal interviews with selected civil rights attorneys. Although some articles from reputable medical journals are also used, often the same ones are cited over and over. Studies are often cited indirectly, through a second-hand source. Very few physicians were interviewed, and almost no MDs are cited in the research. In some sections (particularly those dealing with affirmative action and research grants), the data are either nonexistent or out of date. Finally, the language of the report is in many instances overwrought and, frankly, inflammatory: for example, the “epidemic” of health care discrimination against women and minorities, the bias “infecting” our Nation’s health care system, the “fabric of oppression” which is “ingrained in the lives of women of color,” the “abominable” state of staff training within HHS/OCR, and HHS Secretary Donna Shalala’s “timid and ineffectual” leadership of civil rights enforcement within the Department.

Another specific example of hyperbole and the lack of rigor in the statistical analysis can be found in the report’s recommendation that HHS “mandate” the awarding of grants based on the proportion of women applying. The claim is that women researchers receive 21.5 percent of all NIH research grants and that this is a “blatant civil rights violation.” There are several prob-

lems with this finding. First, the datum is old (from a report that collated information from 1981 to 1992). Second, without a denominator, it is meaningless. One has to know the percentage of the applicant pool that comprised women. Even if that were known, however, that in itself would be insufficient to claim bias since, after all, there should be no expectation that grants be awarded in proportion to the percentage of women who apply. They should be judged on their merits, like all grant applicants.

According to more recent information from NIH (covering 1992–1998), the gap in recipients of grants has narrowed, though this too must remain a qualified conclusion since as many as one-fifth of applicants in a given year were not identified by gender. But in 1993, the year in which only 3.5 percent were of “unknown” gender, 18 percent of the women who applied were awarded grants and 17 percent of the male applicants received grants. Thus, this does not appear to provide evidence of “blatant discrimination.”

Erroneous Claims

Women doctors “pigeonholed”?—The report frequently asserts that women have been “pigeonholed” into lower status medical professions like pediatrics and psychiatry. There is no basis in fact for this claim, and the report fails to explore the extent to which women today may prefer some jobs over others because of family considerations or other personal choices. Further, recent studies show that women are also choosing to specialize in obstetrics and gynecology, a surgical subspecialty, in record numbers, to the point that some complain that male residents have trouble finding jobs. Since this specialty has the highest malpractice insurance premiums (and thus the greatest liability), the increasing number of women specializing in OB-GYN constitutes one of the most impressive signs of the advances women have made in various medical fields.

Women left out of research?—One of the chief complaints of this report is that “women have traditionally been ignored as subjects for clinical trials in medical research.” (See volume I, chapter 3.) The evidence presented by other studies,

* When we submitted our dissent, the word used was “pigeonholed.” It has since been changed to “steered.” Our concern remains, notwithstanding the change.

however, shows that not only have women long been represented in medical research, but sometimes (e.g., in the case of clinical trials on HIV/AIDS) they have been overrepresented. Writing in *The Public Interest* (number 130, Winter 1998), Dr. Sally Satel points to data compiled by the Office of Research on Women's Health at the NIH which show that "women represented 52 percent of the more than one-million participants in NIH-funded research in 1994 (the most recent statistics)." Dr. Satel further notes that "[a]s early as 1979, according to NIH, 268 of the 293 active clinical trials involved males and females; of the remainder, 13 were all-female, 12 all-male."

The way the report frames its discussion on gender discrimination is important because it is illustrative of the way the report frequently tends to make a claim, based on the views of "at least one commentator," without backing it up with additional sources or factoring in any views on the other side of an issue. As a result, there is a constant thread of one-sidedness running throughout the report: "At least one commentator has suggested that the failure to use female test subjects in federally assisted research is a violation of title IX . . . a commentator writing on research and women's health reported studies that have found women patients may be more likely to follow through in obtaining tests suggested by women physicians because they are more comfortable discussing issues of concern with female physicians . . . as one commentator [the same one cited in the previous case] has noted, '[p]hysicians who are women or persons of color improve the availability and quality of health care. . . .'"

The analysis of women's participation in health care research studies is but one example of the report's proclivity toward generalization and the continual reliance on just one or two sources to build an argument (in this case, the "presence of significant barriers" to women's participation in such studies), which could easily be refuted by an equal number of "commentators." This is not to say that no problems exist, but only that we should not diminish the urgent need to address the special health challenges women face by confusing the need for additional research with the false notion that women are second-class subjects in clinical trials.

Failure of Affirmative Action?—In a lengthy discussion of minority recruitment in medical school admissions (volume II, chapter 3), the report justifies a call for broadening affirmative action by emphasizing that "a lack of minority doctors may result in limited access to health care for minority patients." It seems to take the position that affirmative action has not worked (to the extent that the proportion of minorities in medicine is still not high enough) and, thus, that increased affirmative action efforts are needed.

The report claims that the problem lies with the "current hostility of the Federal judiciary toward affirmative action policies in the professional school context." It criticizes the Supreme Court for narrowing the permissibility of affirmative action policies under the Constitution, calling this a "persistent yet baffling denial of the social, economic, and historical realities depriving our medical profession of minority physicians. . . ." It does not address the larger problem of why admissions gaps persist despite race-based advantages or why minority students continue to repeat the first year of medical school far more often than white students.

According to a 1994 report by the Institute of Medicine (*Balancing the Scales of Opportunity: Ensuring Racial and Ethnic Diversity in the Health Professions*), "under a mandate to increase the percentage of minority students," medical school admissions committees admit underrepresented minorities (URMs) with lower Medical College Admissions Test scores and lower grade point averages than their white counterparts. The American Association of Medical Colleges (AAMC) has documented that the acceptance rate for URMs have long been higher than for white applicants with similar qualifications. In 1979 a URM with high grades and board scores had a 90 percent chance of being admitted to medical school while a white applicant with comparable qualifications had a 62 percent chance. By 1991, the last year for which the AAMC has data, the qualified URM had a slightly better than 90 percent chance of admission while his white counterpart had a 75 percent likelihood of admission. Data compiled in 1998 by UC Davis Medical School, UCLA, and UCSF show that in California, even after the passage of Proposition 209, minority applicants were two to three times as likely to be admitted to medical school as whites and Asians with con-

siderably higher grades. Despite these race-based advantages in admission, the Commission's report maintains that "OCR has an important role to play in efforts to ensure more minority physicians in the medical profession" and stresses that OCR should "develop some form of policy guidance for medical schools to address this issue."

It is interesting to look at the results of a recent AAMC study, cited in our report, relating the underrepresentation of minorities in health professions to two factors: "(1) a scarcity of minorities who are interested in the health professions, and (2) the relatively small number of minority students who have the academic qualifications needed to pursue medical study." These findings are important because they underscore that what is needed is not more affirmative action but, rather, real initiatives for increasing the qualified pool of medical school applicants. That means remedial action at the elementary,

secondary, and postsecondary levels of education, not government pressure on medical schools to increase the applicant pool by lowering standards.

Conclusion

The report is an important one insofar as it relates to the enforcement efforts of HHS/OCR. What we are unable to support are those findings and recommendations—in particular, the creation of a "new agency," the implementation of "new, comprehensive civil rights legislation," and broader, federally enforced affirmative action mandates—which go far beyond current enforcement issues to advocate an unprecedented intrusion by the Federal Government into the Nation's health care delivery system. This is not the right prescription for addressing the deficiencies of our health care system or for righting the wrongs of racism and discrimination in this country.

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