U.S. Department of Health and Human Services
Office of Public Health and Science
Office of Minority Health

National Forum on Health Disparity Issues for American Indians and Alaska Natives

"Breaking Down the Barriers – We Are All Related."

September 24 - 26, 2002
Denver, Colorado

SUMMARY

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary
Office of Public Health and Science

Office of Minority Health
Washington, D.C. 20201

JAN 24 2003

Dear Colleague:

I would like to take this opportunity to thank you for your participation in the September 24-26, 2002 National Forum on Health Disparity Issues for American Indians and Alaska Natives held in Denver, Colorado. Enclosed is the Forum summary which includes notes from the plenary and luncheon sessions, and list of workshops.

As you can see from the summary, this meeting covered several topics geared toward the achievement of HHS's over-arching goal of eliminating racial and ethnic disparities in health. This meeting took stock of the progress made through partnerships across the Department and the public/private sector in our stride toward the achievement of equality in health care delivery for the American Indian and Alaska Native populations. The Forum also laid a strong foundation for future efforts. Your participation throughout the Forum emphasized the importance of a larger community coming together to provide new solutions to eliminate health disparities.

At this time of rapid changes in relationships between Federal, State, tribal, and local governments as well as the private sector it is crucial that we develop a common vision and appropriate linkages in our efforts to eliminate health disparities in Indian Country.

Once again, please accept my sincerest appreciation for your attendance and participation in this Forum.

Sincerely,

Nathan Stinson, Jr., Ph.D., M.D., M.P.H.
Deputy Assistant Secretary
for Minority Health

Enclosure

OFFICE OF MINORITY HEALTH
National Forum on Health Disparity Issues for American Indians and Alaska Natives
Denver, Colorado, September 22-26, 2002

Summary Report

The National Forum on Health Disparity Issues for American Indians and Alaska Natives created an opportunity for tribal leaders, urban Indian health organizations, health officials, Federal and State policymakers, and public/private organizations to convene to address the health status of American Indians and Alaska Natives (AI/AN). The Forum consisted of three plenaries, one luncheon session, and 31 workshops. The Forum was preceded by a grant writing workshop. This summary report captures highlights from the pre-conference workshop, plenaries, and luncheon sessions.

Pre-conference Grant Writing Workshop for Tribal Serving Institutions - September 22-23, 2002

This pre-conference grant writing workshop for tribal serving institutions was co-sponsored by the Center for Medicaid and Medicare Services, the Office of Public Health and Science's Office of Minority Health, the Indian Health Service, and the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services (HHS). The purpose of this workshop was (1) to increase the awareness of available funding opportunities in HHS programs through the grant and contract mechanism, (2) to increase the involvement of Tribal Colleges and Universities (TCUs) involvement in HHS program activities and to increase the involvement of TCUs in their pursuit of federal funding across the Federal sector. The workshop was attended by approximately 30 participants, 19 were representatives of TCUs and the remainder were either tribal members or community health representatives.

Tuesday, September 24, 2002

Opening Plenary and Welcome

The National Forum opened with remarks from Dr. Nathan Stinson, Deputy Assistant Secretary for Minority Health, Office of Public Health and Science, and Dr. Hugh Sloan, Regional Health Administrator/Region VIII. In his opening remarks, Dr. Stinson stated that the overall objectives of the Forum are to: (1) identify the health issues associated with sovereign nation status; (2) engage a broad spectrum of participants, including tribes from across the Nation, organizations that provide services, and TCUs; and (3) build and act upon what is learned during the Forum.

Dr. Sloan stated that despite all efforts made to improve health care, the disparity in health and health care delivery continues to be a disproportionate burden upon AI/AN. He stated that many

people share interest in health care and that the co-sponsors of this conference indicate a larger community that can come together and provide new solutions.

The following are common themes from Dr. Stinson's and Dr. Sloan's comments:

The Unique Relationship of Sovereign Nations - Over 800 treaties were signed between sovereign tribal governments and the federal government. In some cases, these treaties actually precede the formation of the United States. A number of federal documents affirm the unique status of AI/AN in regard to health care.

The U.S. bears a special responsibility to the AI/AN population because of the historical and legal precedents and the sovereign nation status of federally recognized tribes and villages.

AI/AN individuals have a consistently higher risk of contracting serious disease and suffering a shorter life span than the general U.S. population. As result of this, the AI/AN community loses its leaders and families suffer the emotional and practical burdens that accompany illness and loss.

Disparity in Delivery of Health Care - Some of the barriers to adequate health care include: under-funding or complete lack of funding, difficulty in recruiting and retaining health care professionals, bias on the part of caregivers and policymakers, and inadequate and aging facilities. Individuals in rural areas face geographic barriers, and urban individuals face heightened cultural barriers.

Behavioral Factors, Treatment, and Prevention - Some of the most serious diseases found in the AI/AN population (diabetes, cardiovascular disease, sudden infant death syndrome [SIDS], and some forms of cancer) can be prevented or lessened by behavioral changes. Lack of funds and personnel within the IHS, and large numbers of AI/AN individuals that do not receive care through the IHS, means that treatment generally is targeted towards advanced disease. Effective education about disease prevention and effective support of behavioral changes are critically needed.

The Importance of United Effort of the Larger Community of Interest - Examples of existing successful programs all suggest that alliances of AI/AN communities, state and federal agencies, non-governmental organizations, health care providers, and academic institutions are essential for any improvement.

Holistic Thinking - Addressing only health concerns cannot solve these health care problems. Improvements in the level of education and in economic prosperity are required. The broader issues concern a much larger spectrum of both public organizations and the private sector. Holistic thinking is an authentic strength of the AI/AN community, and should be used to identify effective action.

Keynote Address - *Addressing Health Disparities in American Indian and Alaska Native Communities , Kathleen Annette, MD, Director, Bemidji Area Indian Health Service*

Dr. Kathleen Annette's opening remarks provided some significant statistics on health disparity. She stated that mortality rates for AIs/ANs, compared to the general population are substantially higher for some diseases, as much as 600% higher. Prevention can substantively change some of these statistics. For example, diabetes can be controlled by diet and exercise changes, and smoking is correlated to a higher rate of both heart disease and Sudden Infant Death Syndrome (SIDS).

Dr. Annette provided examples of successes and possible solutions:

- Individual action through increased use of fitness centers or accessible clinics. When these types of local facilities are provided they are filled to overflowing.
- Communities assign funding for health care. Tribes pay about 80% of the costs for reservation health facilities.
- Increased government participation. She stated that approximately five years ago the federal government put funding into diabetes prevention programs, encouraged individual and IHS participation, and also engaged the resources of other organizations. This joint effort and increased funding made a difference. She identified three symptoms of progressive diabetes: kidney failure; vision impairment; and amputation of the lower extremities due to circulation problems. She stated that from 1994 to 2000 statistics show progressively fewer kidney and vision problems and by 1996-1997 the amputation of lower extremities had significantly decreased.

Dr. Annette preceded in correcting several misconceptions:

- All AI/AN individuals are covered by IHS health care. In fact, there are about 2.5 million Native Americans, but only 1.4 million have access to IHS health care; and
- IHS provides individuals with comprehensive health care. She stated the 2001 per capita expenditure was $1,776, and in fiscal year 2000 Medicare allotted $5,490 per capita. She further stated that funding is so low that the IHS must ration health care.

Dr. Annette sees levels of improvement occurring in an expanding circle of involvement, (Circles of Cooperation), from the individual to the federal level. She used the tribes in Wisconsin as an example. The tribes requested that all the health care partners meet together to discuss the delivery of health care and health care issues. As a result, there was a phenomenal improvement in collaboration and understanding with this focus. For the first time hospitals were included in the discussions and requested assistance in understanding cultural barriers. As part of this new strategy, state government representatives attended a one-day workshop on the delivery of health care and found they could expand services by reducing duplication of efforts.

Dr. Annette offered the following conclusions and recommendations:

- We need to continue to amass reliable data showing that prevention makes a

difference. Collaboration can work if all the partners commit their time and energy.

- ✦ Lack of resources cannot be used as an excuse for inaction.
- ✦ Funding should be used for programs and policies that are proven successes.
- ✦ If the level of education and employment rise, then health disparities will diminish.

Plenary Session I - Panel Discussion: *Federal/Tribal Role: Recognizing Federal and Tribal Responsibilities in American Indian/Alaska Native Health Care*

Leo Nolan, Senior Policy Analyst for External Affairs and W. Craig Vanderwagen, MD, Acting Chief Medical Officer, Indian Health Service (IHS) , provided an overview of *IHS's Role in Delivery of Health Care for American Indians.* Mr. Nolan opened this discussion by giving some examples of collaborations and partnerships underway at IHS. He stated that the National Institutes of Health (NIH) has establish a research program to be administered by tribal nations. NIH now funds this program at $5,000,000 annually. The American Research Epicenter needs major funding. The National Center for Minority Health Disparities/NIH did endow the center with $600,000 to supplement the existing $500,000.

Dr. Vanderwagen stated that IHS' mission is to operate in partnership with tribal nations. The goal is to provide comprehensive, culturally acceptable personal and public health services and that in the IHS system medicine and public health must work together.

He further stated that best practices in Indian Country are based on a community oriented primary care model. The health components include cultural, spiritual, behavioral, social, medical care, public health, water, and sanitation. The most important area, and the one that receives the least attention in public health, is cultural and spiritual welfare.

Mr. Nolan and Dr. Vanderwagen then jointly addressed the following question - How can health disparities be addressed in Indian Country? The key factor that affects health statistics is behavior. Behavior accounts for 50% of the diseases that occur at a higher rate in the AI/AN community. Smoking, unhealthy diet, and lack of exercise can all cause problems like lung cancer, SIDS, cardiovascular disease, and diabetes. At present, diabetes is pandemic, as evidenced by a rising rate of lower extremity amputations. Cardiovascular disease appears to be heading towards the same levels.

Their presentation provided several strategies to eliminate health disparities in AI/AN communities:

- ✦ Possible partnerships and collaborations.
- ✦ Tribal consultations with the Department of Health and Human Services (HHS), not just IHS.
- ✦ Better economic and community infrastructures: If tribal nations directly received block grants and entitlement program funds, economic conditions could be

improved. Two examples are SAMHSA block grants and the $69 billion in annual discretionary programs.

- ✦ Establish tribal government status that is on a peer level with state governments.
- ✦ Form alliances.
- ✦ Improve over-sampling and data systems.
- ✦ Seek executive orders for appropriate issues.
- ✦ Identify tribal community successes, and then share that information.
- ✦ Work with Medicare/Medicaid to raise the collections rate.
- ✦ Adapt business plans and practices, when applicable, in the government environment.

Ms. Yvette Joseph Fox, Executive Director, National Indian Health Board (NIHB), provided an overview of the goals and objectives of the NIHB. NIHB consults on policy analyses and program development, assures that health care advocacy is based on tribal input, advances sovereign concerns of tribal governments, and increases the knowledge of Indian Country by policymakers in the federal government. NIHB also distributes health care information and legislative information to the AI/AN community.

Ms. Fox stated that during the winter of 2001, the Bush Administration wrote a letter that (1) acknowledged the federal trust responsibilities and (2) supported the federal funding level without a state subsidy. She stated this is a very significant policy statement because it reaffirms the prior Administration's commitment, in the form of NGA Resolution HR-31.

Ms. Fox provided an update of *Current Issues and Initiatives in Indian Health.* She stated the following:

- ✦ SR2711, sponsored by Senate Indian Affairs Committee Chairman Daniel Inouye and Vice-Chairman Ben Nighthorse Campbell, seeks to reauthorize the Indian Health Care Improvement Act for an additional three years. The bill has been placed on the Senate calendar, but several provisions have raised objections from the Administration or other Senators. Tribal governments should watch the progress of the bill carefully.
- ✦ NIH has released an extra $14 million for community health programs through the Native American Research Centers for Health (NARCH). These are recurring funds. Tribal communities are eligible for a $550,000 supplement. The funding is disbursed three times a year.
- ✦ To help improve the grant writing process, she recommended that Forum participants encourage tribal leaders to send letters to the Health Resources and Services Administration targeting their review process. Tribes can request that there be six AI/AN representatives on the grant review boards. The best way to learn about these programs is to participate in application reviews by being on these boards. This experience would make it much easier to prepare a good grant application.

Ms. Fox stated that NIHB could send email updates to participants during the legislative session. It also publishes health reports and has an up-to-date mailing list see www.nihb.org.

She further stated that in the current legislation session, the Health Priorities bill would need support if it were to be enacted. It is important to write letters of support. Other bills that need support are:

- Indian Health Care Improvement Act is up for reauthorization
- Native American Alcohol and Substance Abuse Program Consolidation Act
- Elevation of the IHS Director to an Assistant Secretary rank (this is supported by the Bush Administration)

Ms. Fox went on to say that tribal governments are seeking a status equal to the states in funding for homeland preparedness/bioterrorism. Tribal leaders are working with Senator Tom Daschle for a $1 billion increase in IHS funding. Work continues with HHS, DoD, DoI, and EPA. There is also a desire to change the Appropriations Subcommittee from Interior to Labor and HHS. She stated that NIHB publishes a Washington Report with all of the current news on federal government actions that are important to the AI/AN community. Forum participants or other interested parties can contact NIHB to subscribe to the newsletter on current issues.

Ms. Fox concluded her remarks by stating that the Indian health policy should be distinct from that of other sub-populations because of the unique legal status of this group. Senators Daschle and Domeneci, among others, support NIHB's efforts.

Carol Ann Heart, JD, Executive Director of the Aberdeen Area Tribal Chairman's Health Board, expanded upon the legal and constitutional basis for the federal government's responsibilities toward tribal nations. Current national issues highlighted by Ms. Heart included:

- Dams have flooded millions of acres of reservation land. The federal government promised to rebuild flooded facilities but still has not done so.
- When comparing 1994 to 1996 health disparities the IHS funding trend is flat when calculated for factors like monetary inflation and a rising population.
- Self-identification on the 2000 census took the AI/AN population from 2 billion to 4 billion.
- The IHS has an allotment for health care of about $1,200 to $1,500 per person. By contrast, the allotment for a federal prisoner is $3,500.

Ms. Heart identified the following barriers to health care in Aberdeen, South Dakota.

- Trust responsibilities have not kept pace with a rising population.
- Trust obligations have been diluted in the legal system.
- Rural isolation
- Poverty
- Cultural differences between caregivers and patients

She stated that the tribes in the Aberdeen area are predominantly non-self governing on health care matters. This compromises which facilities and health care professionals are accessible.

Ms. Heart concluded her remarks with the following recommendations:

- Raise the standard for health care and uphold federal obligations to the tribes.
- Assist in strengthening the infrastructure of tribal governments and lands.
- AI/AN need help from all of the federal and state agencies.
- Develop businesses in Indian Country and provide economic development.
- Re-evaluate the effectiveness of health care delivery. Look holistically at providing critical care, ambulance services, hospital beds, long-term care, and traditional healing.
- Ensure competitive salaries for health care providers to ensure stability in staffing. At present the tribal government cannot compete against nearby Rapid City for greatly needed physicians, nurses, and pharmacists.
- Tribal members need to seek education in the healing professions and return to practice in their own community.
- Educate staff and patients through extensive outreach.
- Optimize Medicare and Medicaid funding and collections.

Wednesday, September 25, 2002

Opening Remarks

Joseph Nunez, Regional Health Director, Region VIII, provided opening remarks and introduced Claude A. Allen, Deputy Secretary, Department of Health and Human Services' remarks regarding HHS's Health Disparity Initiative via video.

Deputy Secretary Allen's opening remarks stated that the National Forum reflects the department's deepest intent to develop long lasting and productive relationships and partnerships that will help achieve HHS's goal of eliminating disparities and achieving good health for all Americans.

He stated that when we look at major health concerns in America, what is most striking is that they can be prevented by lifestyle changes, diet, access to care, and improvement to the health care system.

Mammography, annual pap smear, PSA test, HIV/AIDS testing, smoking cessation, exercise and pre-natal care are all life saving precautions that must be taken. Personal and community responsibilities as well as better education are keys to eliminating health disparities.

Deputy Secretary Allen gave examples of HHS's efforts currently underway in AI/AN communities to combat disparities. He stated that IHS, working with CMS, has been granted status as a national accreditation organization, to deem AI/AN diabetes outpatient self-management training entities. With IHS's solid record of experience in diabetes, this authority will enhance program quality and increase the number of accredited programs in the AI/AN communities. The American Indian Higher Education Consortium, through its cooperative agreement with the Office of Minority Health, has received funds from the Centers for Disease Control and Prevention (CDC) to coordinate and administer a project to reduce the impact of diabetes in tribal communities. CDC will continue demonstration projects for minority populations at risk for infant mortality, diabetes, HIV/AIDS, CVD, deficits in breast and cervical cancer screenings and management, and deficits in child or adult immunization rates.

He stated that nearly 30% of Indian elderly live alone and nearly half consider their health to be fair or poor. In an effort to remedy this situation, in April 2002, the Administration on Aging awarded nearly $28 million to support vital community services and programs for Indian elders and their caregivers. The Administration for Native Americans is in its third year of funding the National Indian Health Board, a project to strengthen tribal management capabilities and health and human services delivery by creating a health care curriculum for the twelve area Indian Health Boards, member tribes, and other tribal organization. He further stated that this year HRSA supported a special program to increase access to primary care for AI/AN communities with HIV/AIDS or at risk for infection. Five sites received funds along with an AI/AN technical

assistance center. Also through HRSA, the Department will continue to maintain its commitment to strengthen rural health care, including in Indian country, with developmental grants and the President's plan to expand the network of community health centers.

In closing, Deputy Secretary Allen encouraged Forum participants to be creative in approaches to promote health, encouraged personal responsibility in their communities, listen to community needs, strengthen vital health services in AI/AN communities, strengthen the capacity of tribal colleges and universities, and engage in frank discussions. These are the hallmarks of the partnerships that the Department wants to build.

Plenary Session II - *Overcoming the Challenges: Tribal/Urban/State/Federal Perspectives* - Panel Discussion

Donna Polk-Primm, Executive Director of the Nebraska Urban Indian Health Coalition emphasized the importance of cooperative ventures. As an example, she stated that in the Aberdeen area of Nebraska, the Area Director included urban programs in all consultations and that inadequate funding demands coordination of priorities, structure, and budget to maximize efficiency.

Ms. Polk-Primm stated that the major obstacles to health care are racism and politics. Few, if any, people of color have positions of authority on hospital boards, in insurance companies, and state, and federal governments. Those are the groups that make funding decisions for emergency rooms, outpatient clinics, equipment purchases, etc.

At the tribal level, decisionmakers prioritize how health insurance is applied. The top priority one year might be analysis, and the next year might be cardiovascular care. There is insufficient money for all needs. She further stated that if a person needs heart surgery, and dialysis is the priority, then that individual's medical care is at peril.

Dr. Polk-Primm provided examples of specific strategies and identified needs:

- Having a good overview helped her get the services she needed for her clinic. She asked the hospitals to help her medically underserved community. However, after putting some funding into the community, that support ended. She was then able to leverage that funding history into a better level of Medicare/Medicaid funding. Dr. Polk-Primm recommended that HRSA create a set aside fund for urban clinics, in addition to their existing programs.
- Clinics also need tort coverage, so that care providers can be protected. Malpractice costs are exorbitant.
- Patient care and pharmacy inadequacies need to be addressed.
- Inpatient capacity needs to be increased. At present her clinic has 14 substance abuse beds, and this is inadequate. There is an increase in heroin and methadone

addicts and alcoholics. This is a big problem for the reservation. Addiction problems are compounded by gang activity.

- Reservation residents, justice officials, mental health providers and young people all need to be together at a tribal meeting to talk about drug use and gang activity. Many tribal people have no knowledge of methadone, and are unaware that there are methadone labs on Nebraska reservations.
- The community needs support for after-care transitional living and more regular housing.
- More reservation members need to be educated. People need to acquire GEDs, college degrees, and health care training.
- Elder programs are needed like nutrition education, meals, crafts, and outings. The existing USDA requirement is for elders to pay $5 for a lunch. This is too much for many of our elders; we need to get more assistance from the USDA.
- For the past three years the West Nile virus has been a great concern. Three people in Nebraska have died. Hepatitis C, HIV/AIDS, and Hantavirus are all concerns. One flawed national strategy is to immunize people for smallpox at polling places. Urban Indians do not vote, and do not know where those polling places are.
- Tribes need to be at the table as bioterrorism and homeland security policy is made. Reservations need reliable fax, email, pager, and cell phone capabilities.

Rita La France, Executive Director of Health and Human Services for the St. Regis Mohawk Tribe, addressed some of the problems that exist between tribal and state governments. As her tribe is located along the St. Lawrence Seaway in both the U.S. and Canada, border issues and conflicting multi-jurisdictional issues abound. Ms. La France was disappointed that not enough state officials attended the Forum. She stated that success in health care is related to persistent and assertive lobbying. Only 39% of the tribe's health care dollars comes from IHS. A large percentage is uninsured, and about one half live on the reservation.

Ms. La France stated that there are two industrial plants (Alcoa and GM) within the reservation boundaries. A superfund site is adjacent to the reservation due to the environmental contamination of the water. The tribe suffers from a high rate of neurological disabilities, mental retardation, autism, and developmental disabilities. The Mohawk/Iroquois community wants the Office of Mental Retardation and Developmental Disabilities in New York State to address these difficulties. New York State knows very little about the St. Regis Mohawk Tribe. There is no tribal consultation policy in the state. The tribes are not asked about services and decisions that directly affect the community. The tribes are now trying to repatriate services that have been taken away. Only then will policy be developed and appropriate treatment will be delivered.

Ms. La France's tribe has shared their culture with state officials, and has found some interest, but there is still no formal mechanism to make any changes. When the present Commissioner leaves office the commitment will be lost as well, unless a new administrator wants to work with the tribes. She stated that the tribe has to extend themselves first, and then work on a formal commitment.

Ms. La France further stated that the tribes are told things at the last minute, and are not engaged in setting priorities. Often government officials do not answer e-mails or phone calls. It is up to the tribes to get the state and federal agencies to sit down with us and develop an agenda. Tribes, state, and federal agencies must work together, and approach the work in a peaceful and respectful manner.

Dorothy Dupree, Senior Policy Advisor Centers for Medicare and Medicaid Services, pointed out that there are a plethora of technical experts within the agency. Each expert holds a very narrow and specific area of knowledge. Often these experts have a great deal of interest in tribal issues, but do not know whom to talk to within the community.

She reviewed the trust responsibility: the Indian Health Care Improvement Act covers Medicare/Medicaid billing, state Medicaid, and the Federal Matching Assistance Percentage (FMAP). Congress will reimburse the states for 100% of Medicaid costs at IHS facilities. Ms. Dupree stated that a lack of knowledge exists between tribes and the Medicare/Medicaid system.

Ms. Dupree sees opportunities for collaboration through distance-based learning, a satellite initiative, and educational conferences. The states of Alaska, Oklahoma, and the city of Aberdeen have had success in getting income through grassroots organization.

She noted that Federal agencies do want to listen to the tribes. It is up to the tribes to help them. CMS regional offices have tribal consultations. Other advocacy groups include the National Association for Rural Health, community health centers, partnerships with states, and TCUs.

She further stated that estate recovery waivers remove a barrier for elders so they can collect Medicaid. A tribe can be designated as the on-site authority for Medicaid waivers. A Minnesota tribe has requested that they be able to determine Medicaid eligibility. The federal government is waiting now for others to come forward.

Carol Ann Heart of the Aberdeen Area Tribal Chairman's Health Board provided an historical and legal background for tribal status in the United States. The goal in health care is to increase access and improve long-term health outcomes by decreasing the gap in health status.

Ms. Heart's recommendations include:

- ✦ Performing consumer surveys in hospitals, publish the results, and find out what consumers identify as most important in health care.
- ✦ Increasing community based health care providers.

She then highlighted examples of success:

- ✦ In Aberdeen a grant of $986,000 from tobacco funds is used for case management of diabetes.
- ✦ In New York State the New York Department of Health gave over $1 million to developmental disabilities and $1.5 million to child welfare services after lobbying by the tribe.

- ✦ In the Billings area the actual participation in the IHS Healthy Start Fund is $2.2 million.
- ✦ Tribal meetings have been held at the central office level of Medicare/Medicaid. There is a joint steering committee for CMS policy.
- ✦ In Alaska there have been 1,500 rural childcare screenings in remote villages.

Luncheon Session - *Overview of the IOM Report and Its Impact on American Indians and Alaska Natives, Jennie R. Joe, PhD, MPH, University of Arizona*

Dr. Jennie Joe reviewed the two research approaches used to gather information for The IOM Report entitled *Unequal Treatment Confronting Racial & Ethnic Disparities in Health Care.* The first was an exhaustive literature search on health disparities. This approach was necessary to establish clearly whether or not disparities do exist. Attention can then be paid to correcting problems instead of debating about their existence.

The second approach was to examine what happens when people enter the health care system. Are there systemic problems that obstruct access? The research established that much more work needs to be done to eliminate disparities.

Dr. Joe stated that bias, discrimination, and stereotyping are all sources of disparities in health care delivery. Improvement will come with: 1) appropriate clinical behavior on an individual level; 2) optimization of the health care system; and 3) a legal and regulatory climate on a systemic level.

Data sources for this study included existing evaluation-based studies, commissioned papers, consultation with experts, committee members, input from organizations, governments, professionals, focus groups, and meetings with agencies like the IHS. The evidence for health disparity included IHS data. This data showed excessive mortality (morbidity compared with life expectancy) and inadequate funding. Historical analysis showed social and cultural disruptions, chronic poverty, and longstanding neglect since World War II.

Dr. Joe stated that there was little evidence-based data. This could be due to a small population, a separate health care system, and/or racial misclassification. No data was available on care outside IHS or on discrimination in the quality of health care.

The study attempted to fill data gaps with focus groups and cross section surveys. The findings as summarized by Dr. Joe are:

- ✦Limited funds have forced rationed health care.
- ✦There are differences in treatment between internal IHS care and external clinical care.
- ✦Discrimination is subtle.
- ✦Patient satisfaction is not routinely measured.
- ✦There is little follow up on patients referred out of the IHS system.

Dr. Joe further stated that IHS patients receive good quality care. However, the quality improves with tribal control, with the caregivers becoming more responsive to local needs. With tribal control there is less waiting time and an increased continuity of care.

Some of those interviewed said that constant change in tribal governing bodies creates political instability. The turnover in decision makers makes it difficult for leaders to have enough knowledge and experience to make good judgments about health care.

Outside of IHS care there is less confidence in the quality of care delivered, and more reports of discrimination. Two examples of this are: 1) designated "Indian beds" in a hospital; and 2) clinics and hospitals that require extra evidence of health insurance or ability to pay before admitting AI/AN patients.

Dr. Joe said that bias and stereotyping in external care is seen in assumptions that an AI/AN patient's problem is alcohol related, or that the patient is less educated or less capable of dialogue. One consequence of this kind of bias is that caregivers do not attempt to offer a thorough consent briefing to inform the patient. The evidence-based data collected confirms the existence of health disparities.

Dr. Joe provided the following summary of the IOM study recommendations:

- The efforts to address diabetes can be a model for approaching disparity. A special Congressional initiative established a separate fund to implement prevention, not just treatment.
- The lack of funds creates a large gap in health care delivery. At the Congressional level, greater resources need to be directed to HHS and the Office for Civil Rights. The law needs to be enforced when hospitals deny care.
- Bias and stereotyping create clinical uncertainty and have a negative impact on the quality of care. Increased numbers of minorities in all of the health care professions will help address this problem. Other recommendations are to increase the use of interpretation services and to integrate cross-cultural training into the caring professions.
- Data should be collected and reported on access to health care.
- More research should be done to identify promising intervention strategies.
- Problems that were identified in surveys in Indian Country include access, the difficulty of enrolling in Medicare/Medicaid, language barriers, and cultural competency. Cultural competency is not clearly defined, and is harder to interpret.

Other challenges that exist in Indian Country are:

- The IOM Study advocates a need-based delivery of health care. Tribal governments need to seek legislative authority so they may negotiate rates for services. A small community needs to have better control over costs so that one accident or other major medical event does not wipe out the entire annual fund.
- Quality of care needs to be documented, instead of assuming it is acceptable between a patient's entry and exit from the system.
- We all need to talk more about discrimination. If perceptions of discrimination are not addressed it is a disservice to all of those involved.
- Techniques for monitoring quality of care should be used to improve care infrastructure.
- Target the health disparity gap in accidents, trauma, and substance abuse.
- Data should be collected about healthy people.
- The importance of traditional medicine should be acknowledged.

In closing, Dr. Joe posed the following questions to the Forum participants:

- What tools and information are needed to fix the health disparity?
- How much can be done without additional resources?
- How can more evidence-based data be amassed?

Thursday, September 26, 2002

Plenary Closing Session *Eliminating Health Disparities Among American Indians/Alaska Natives: Next Steps, Where Are We Going?* – Panel Discussion

Joseph Garcia, Vice President, National Congress of American Indians, stated that partnering is essential for effective improvements to health care. It is not always obvious that we have a lot of resources. These resources need to be consolidated and harnessed. The trick is to identify the issues. If we do not find the root causes of health disparities we will not solve the right problems.

Mr. Garcia proposed some change initiatives:

- ✦ Realize and accept that there is change occurring all around us, all the time.
- ✦ There are some things we wish to change; and some things we do not want to change such as values, principles, traditional beliefs, and culture.

Some of the critical questions for this process are:

- ✦ Is there a need to change or are you completely satisfied with the way things are?
- ✦ Is your organization advancing or is it in status quo?
- ✦ Are you providing the necessary services, and are they quality services?

There are methods, systems, and strategies to suggest solutions. The task is to choose the right ones. Mr. Garcia suggested that there are six approaches to dealing with change: avoidance, apathy, resistance, reaction, anticipation, and creation. He encouraged Forum participants to work the hardest towards the last one, creation.

Each member of the panel outlined key action items.

Joseph Nunez, Regional Director/Region VIII, would like HHS to improve outreach to communities and improve communication and coordination both inter and intra-agency in order to work better with tribal governments.

Kay Culbertson, from the National Council of Urban Health, would like to see the Tulsa demonstration project made permanent. She would like to see the tribe's role in IHS increase, and see IHS include urban Indian health programs more effectively.

Ralph Forquera, from the Seattle Indian Health Board, stated that the U.S. national health care system as a whole is in crisis. Some serious problems are: economics; consolidation of health care providers; avoidance of leadership in addressing malpractice and other issues; and a failure of the health insurance model. Mr. Forquera recommended that Forum participants (1) work creatively, and partner with both minority and mainstream communities, or health care will continue to decline, and (2) increase the number of AI/AN family practice physicians.

Delight Satter, MPH, University of California at Los Angeles, stated that academic circles are talking about new dissemination strategies, so that their research and findings will reach a larger

community. She stated that: (1) academicians need to identify and disperse new data collection methods that work well for small populations, or subpopulations, like American Indians; (2) academicians need to remember their responsibilities to public service; and (3) we all need to take care of ourselves as individuals.

Donald Warne, MD, MPH, NIH, based his recommendations upon his work with a federal diabetes study in the Pima community in Arizona. His observations are as follows:

- Intervention programs are long overdue. Hiring more Native Americans is long overdue. Disparities in health care exist because of disparities in the resources for prevention.
- There needs to be better coordination of services--different agencies are in charge of small components.
- There needs to be more physical activity programs for children. We still need funding for physical education teachers.
- We are spending funds on tertiary care (care for those in the final stages of illness) rather than on prevention. This is a bigger problem. We need prevention, not pills. In secondary and tertiary care (care for the moderately and severely ill) there is no care coordination. There is no funding for case managers, but at the same time there is money for dialysis machines.
- Funding programs should be renewable for the long term, not just for a few years.
- Agencies and even hospitals operate in silos (in organizations that do not touch any other enterprise). People need to be hired and trained in working with community problems.
- Limited transport is a barrier to care.
- Funding is greatly needed.

Ms. Yvette Joseph Fox, MSW, Executive Director, National Indian Health Board (NIHB), stated that consolidation could have a devastating impact on AI/AN health care. Diabetes is present in almost every family, and heart disease appears to be increasing as well. There is a pressing need for more oncologists and other cancer specialists. Some examples of successful programs are: the Whirling Thunder Wellness Program, the immunization program, and the Thunderbird Treatment Center.

Ms. Fox emphasized that it is important for the AI/AN community to understand the federal budget. Budget goals on a national level include:

- Inclusion in homeland preparedness and bioterrorism for the tribes. Only one of the 50 states – Wisconsin – has made funds available.
- A focus on healthy communities.
- Protecting and empowering specific populations.
- Decreasing health disparities.
- Support for families.
- Indian medical facilities are too old and need to be renovated or replaced.
- Denial or rationing of medical services should stop. Preventative care is lost in these circumstances -- care is given by "life or limb" rules. This means that if a life or limb is not endangered the person is not treated.
- Urban Indians are even less cared for than those who live on reservations.
- There is disparity in medical funding. An AI/AN is funded at $1,000 - $1,500 per

individual, whereas, Medicaid budgets $3,221 per individual. Full funding can be achieved. There is a 10-year plan for a phased-in, fully funded budget for AI/AN health services. We are competing against other needs in that budget. $1 billion a year could achieve parity, the same level of funds as Medicaid. As a comparison, South Dakota was just given $6 billion for drought relief.

- ✦ Between 1994 and 2001 IHS was downsized by 60%. IHS should now be exempt from downsizing, and in fact should be doubled.

Comments from the Floor

The following comments and recommendations were made by Forum participants:

- ✦ Successors and leaders are needed in AI/AN communities. This means adequate Head Start funds, counselors, better education for children, and more high school and college education. Other needs are 1) adequate resources to educate the community so that they can become self-sufficient, 2) home health support, and 3) coordination with the local college, even if it is not a tribal college.
- ✦ Course work and training be provided out on the reservations. These would include online training and online academic courses.
- ✦ Education disparity should be addressed at the local level. Systems are too fragmented in business and services. Congress needs a comprehensive list of all disparities so that a realistic approach to funding and programs is achieved.
- ✦ Oral health status of AI/AN children is a major concern. Early childhood care is in the range of 60-80%. The AI/AN population has the highest use of tobacco, the highest rate of oral cancer, and the highest rate of otitis media infection. All of these difficulties are behavioral matters. By the age of two it is too late for the child to recover from the damage done.
- ✦ Comment from a single participant ...the conference, first of its kind was good, yet a bit frustrating. Participant hoped for education on disparities and more time spent problem solving. He stated that the next project should concentrate on designing and implementing strategies to affect federal agencies.

Concluding Remarks

Dr. Nathan Stinson, Deputy Assistant Secretary for Minority Health stated that this forum was not an end, but an additional step forward. There is an increasing awareness of disparities, including emerging disparities. Increasing funding is not under debate as an agenda item for HHS. It is not only equitable but also mandatory for this Nation to increase health care if it is to remain a principle of the Nation.

He further stated that it is important to take these discussions back to our governmental departments. This has to be done in concert with other advocacy groups. Many recommendations have been made year after year, but they have not fallen on fertile ground. When the Nation comes to a point that it sees the level of unmet need there will be the momentum of national will. He referenced ongoing work in the area of immunization as an example. He stated that immunization work was piloted in the AI/AN communities. This led to

improvements for everyone in the U.S. This same approach could be used again to improve the lives of American Indians and Alaska Natives.

Dr. Stinson thanked Forum participants and stated that their participation throughout the Forum emphasized the importance of a larger community coming together to provide new solutions to eliminate health disparities. He stated that the Office of Minority Health is committed to eliminating health disparities for all populations and the discussions, recommendations, and comments made during this Forum will help us fulfill this commitment.