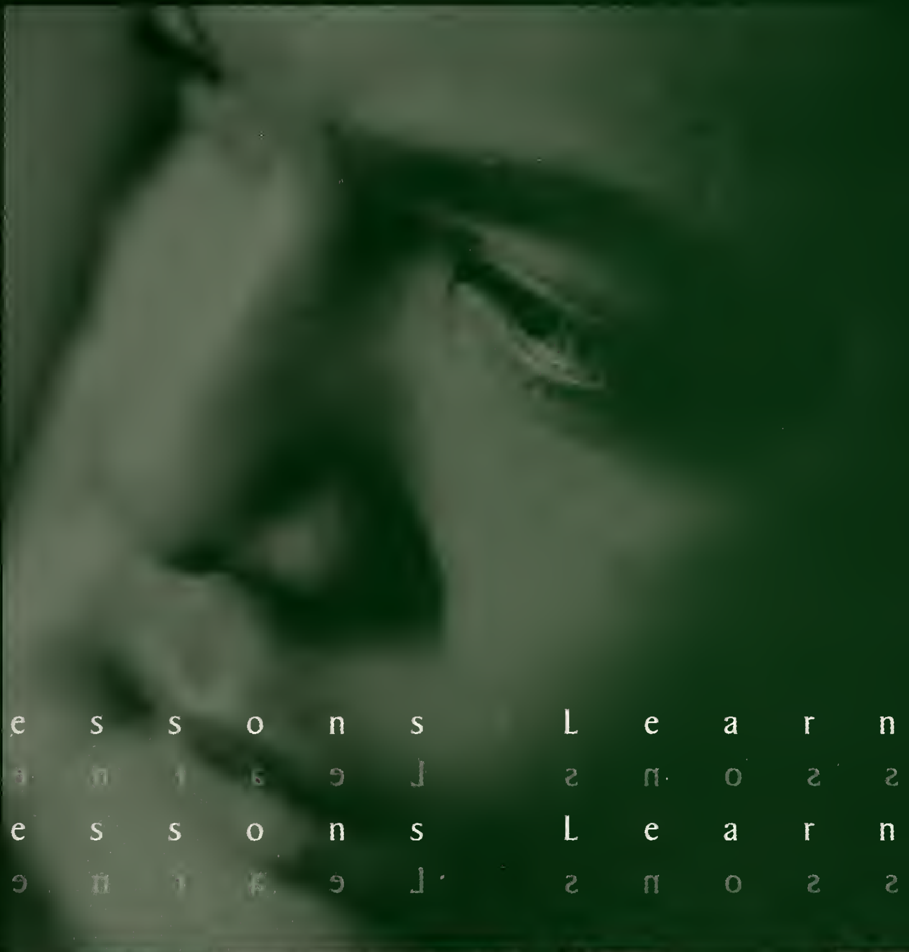

Lessons Learned

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HRSA HIV/AIDS Bureau, SPNS Program and Department of Housing and
Urban Development, HOPWA Program

U.S. Department of Health & Human Services
HRSA
Health Resources & Services Administration
HIV/AIDS BUREAU

Lessons Learned: Innovations in the Delivery of HIV/AIDS Services

March 9, 2001

Dear Colleague:

The Special Projects of National Significance Program (SPNS) in the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) has a unique role in the field of HIV/AIDS service delivery—the support of innovation. Through five- and three-year funding initiatives targeting themes as diverse as service integration, palliative care, and border populations, the SPNS Program is able to provide experienced and committed HIV/AIDS providers the freedom to create and test new models of care designed to meet emerging issues and the needs of underserved populations. SPNS grantees identify the challenges, develop models to meet these challenges, implement and refine these models over a number of years and evaluate their impact. This work is complicated, difficult and absolutely essential.

The obligation of those who travel the road of innovation is simple: tell us what you have learned and help us replicate the successes and avoid the failures. This document is one of the ways in which a group of SPNS grantees is meeting its obligation to the HIV/AIDS service provider community.

The projects represented in this collection provide a wonderful insight into the richness of the innovation supported by SPNS and the depth of learning that has taken place over the four years these projects have been in existence. In these pages we have the opportunity to read about providing HIV/AIDS care to homeless youth, Asian and Pacific Islander populations, migrant workers, ex-offenders, Native American populations and multiply diagnosed individuals. These reports address issues as diverse as service integration across large geographic regions and the provision of high quality mental health care to indigent populations. We also hear in these reports from providers working across the nation, in the rural south and in urban centers on both coasts and in the mid-west.

The lessons taught here come from real-world experiences and represent the kinds of problem solving that has enriched the service delivery field time and time again. Also characteristic of the field are the collaborations that run through every stage of these models even to the creation of these documents.

The projects represented here are part of an initiative in which the SPNS Program partnered with the Housing Opportunities for Persons with AIDS Program in the US Department of Housing and Urban Development (HUD). Each of these projects has also worked closely with members of the Evaluation and Technical Assistance Center (ETAC) at Columbia University's Mailman School of Public Health on the evaluation of these interventions. In fact, the authors of these pieces are drawn from ETAC and each of the SPNS and HOPWA funded projects profiled here.

The SPNS Program exists to ensure better care for people living with HIV/AIDS. At a fundamental level this is about getting care to those who do not have it. The lessons shared here are about accomplishing this goal. I am sure you will find them as inspiring as I have.

Sincerely,

Barbara Aranda-Naranjo Ph.D., FAAN

Barbara Aranda-Naranjo, Ph.D., FAAN
Branch Chief, Demonstration Project Development and Evaluation/SPNS HRSA/HAB

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The First Steps to Replicating New Models of Care

Introduction by Robert Sember

Over the past four years, each of the twenty-five projects represented in this monograph have designed, implemented, refined and evaluated an innovative model of HIV care. The development of these models has involved taking well-established service delivery techniques, such as street outreach and multi-disciplinary care, and redesigning them for use in settings and with populations that are among the most marginal and isolated in the AIDS epidemic.

The providers represented her work in diverse settings across the country including along the US-Mexico border, in sparsely populated areas of the rural south, the extensive suburbs of the San Fernando and Antelope Valleys north of Los Angeles, and prisons in the states of Rhode Island, Washington and New York. The individuals served in the course of developing these models are drawn from the ranks of homeless youth, the largely invisible rural poor (which include many American Indians and migrant farm workers), women and children living in poverty in the inner cities, and the adult homeless living with drug addiction, and mental illness.

The Collaboration

In addition to creating these new models of care in their own agencies and settings, key staff from these projects have worked together to build the principles of care they wish to offer to others in the HIV/AIDS service delivery field who work with similar populations. Collaborations on this scale are rare. This one is the result of a collaboration between two federal programs: the Special Projects of National Significance Program (SPNS) in the Health Services and Resources Administration (HRSA), and the Housing Opportunities for Persons with AIDS Program (HOPWA) in the Department of Housing and Urban Development (HUD).

The combination of federal resources across agencies brought together a diverse group of providers under a number of initiatives. These initiatives focused on youth, integrated services and multiply diagnosed clients. While distinct, they proved complementary, meeting around the common problematic of how best to serve HIV-positive individuals with many needs, especially when those needs are in competition with each other, such as when individuals are struggling to survive both poverty and meet the conditions of HIV therapies.

This collection of pieces documents how these very different projects have taken up the issue of multiple, competing client needs and have attempted to fashion workable responses in the form of service delivery systems. The pieces are communications with others in the field. They are built on the shared acknowledgement that this work is complicated and effortful. Evident in all of them is the fact that this work is not neat; it does not progress along simple, clean lines from beginning to end. Like the lives of the individuals served, the lives of these programs, as well as the process of keeping them going from day to day, include frustrations, disappointments, unexpected disasters (such as the tornado that leveled a clinic used by one of the projects), and great will power.

From Concept to Implementation

Each of the pieces collected here is made up of three components, presented in the following sequence: a description of the project, a set of key lessons developed as a result of its implementation, and a chronology or timeline of key events experienced over the life of the project.

Reading the pieces from beginning to end takes us deeper into the processes that lie behind the architecture of the model's final form. The description of the program outlines what the model has become as a result of the work of four years. The lessons learned section, while also the result of four years of work, provide us with a rationale for the lessons by describing the successes and failures that were part of the process of learning. And the timeline provides a glimpse into the step-by-step process of bringing key program components to fruition. Some of the timelines are very effective in documenting the effort, the length of time and the convoluted process required to put certain elements in place.

By showing how to move from the concept for an intervention to the intervention itself, these descriptions provide a blueprint for what must be done if the model is to be replicated. Hopefully, they also diminish the inhibiting effects of reading about programs that appear seamless and smooth functioning when we know full well that if we attempted to do the same it will entail great difficulty. Two-dimensional representations of program designs can be particularly intimidating as they lack the depth necessary to show what lies behind the neatly arrange facade. The authors of these pieces are intimately acquainted with the mess behind the model and are generous enough to show us their process of learning so that we can better appreciate the strengths of the interventions and be inspired enough to try them ourselves.

Common Lessons

While the pieces may be appreciated as individual project narratives, documenting the efforts of particular service teams working in specific settings, the common format also makes it possible to read them together. Reading across the processes described in the various models is very instructive.

We are able to see the differences between local settings with greater clarity when we can contrast them with the process followed somewhere else. We are also able to see the common lessons that accumulate when the multiple processes are brought together. Most interesting, however, is holding both the common lesson and its particular illustration in place at the same time. For example, almost all of the models described here required developing linkages with multiple service agencies. The objectives are similar across the projects, as are some of the service settings. The process, however, can be quite different.

The common lessons that emerge from reading across the Lessons Learned pieces may be clustered into four broad areas:

> *1. Implementation*
>
> A great deal of work is done before seeing the first client. Many elements go into making a service delivery model and bringing those elements together requires skill. This process begins with the writing of the proposal when, for example, letters of support are obtained from potential collaborators. It continues after the notice of award when certain revisions may be requested by the funder. Planning is required before putting program elements in place and initiating the first intake. And even then, it is likely that significant adjustments will need to be made before the service process is able to function at capacity.

2. Service System:
Given the complexity of AIDS as well as the multiple needs of the client populations served by these projects, it is essential that providers offer comprehensive services or refer clients to other providers. While it would be most convenient in some cases to offer all services under one roof, this is not possible for most organizations and a system of care will have to be developed in collaboration with other providers. In addition to this specific service system, agencies and projects also operate in relation to the broad community and service environment (both HIV/AIDS specific and non-HIV/AIDS).

3. Agency
All of these projects are carried out within established services organizations that bring with them both enabling and constraining features. They also have differing levels of experience in work with the targeted population. Among the most important resources an agency has is the collective skill of its employees. The management of these skills along with the financial and other resources an agency has can have a significant impact on the life of a project.

4. Client
Service organizations do not operate independently of the clients they serve. An agency negotiates between the needs of the clients and the resources it is able to leverage to address those needs. It is seldom that clients simply fit in to a carefully designed system of care. Instead, through trial-and-error, clients and providers will work together, most often informally, to adjust the service delivery process. For multiply diagnosed, homeless clients, for example, running a service system using appointments is highly unlikely to succeed. At least some portion of the service will need to be accessible by drop-in clients.

Implementation Lessons

Program goals

Few lessons hold true for all projects and all settings: two that may be universal concern resources and time. In the world of not-for-profit community based service delivery, it is true that there are needs that cannot be met because of limited resources. Program funding, however, is only partially driven by level of need. Priority setting and policy decisions are extremely influential in defining intervention initiatives and funding levels. When requesting funding, agencies work to describe their needs and the needs of their clients in ways that fits the parameters of a particular initiative. The intervention proposed is based on multiple pieces of information: the agency's capacity to provide the services, the needs of the client, application requirements and the potential level of funding.

Scope of work

As explicitly documented in a few of these pieces, the funding granted is seldom at the level requested. Those who write about this aspect of the implementation process offer a number of lessons based on the funding level. The first is that after receiving the award, the original plan must be revisited and the scope of work adjusted to fit the award amount. It is important to identify realistic expectations. This can be particularly hard if it requires eliminating or significantly altering a favored element of the proposed model. The consequences of not making undertaking this revision are significant. Usually client recruitment levels cannot be met and the project is understaffed.

Implementation time

A second consistent lesson concerning implementation is the time required to first put the model in place. As is often stated in the lessons learned sections of these pieces, this always takes longer than anticipated. Without providing adequate time and resources for the implementation phase, however, the project will be vulnerable to difficulties in later stages of the development process. It pays to have critical components of the project resolved and in place before serving clients.

The time required for implementation differs based on the nature of the intervention. Infrastructure development, such as renovating or building a new facility takes the longest, more than three years in some cases. Large linkage projects, such as those involving the development of computer networks across multiple sites, also takes a great deal of time to put in place. Projects that serve clients within already established service systems have the shortest start up times, averaging about six months. The innovations in these projects are in population targeted or a specific service component. While the implementation may be easier, the refinement process can be difficult. As a new population of clients is integrated into an existing service structure they bring new needs to the system. If substantial enough, these needs will eventually stress the system sufficiently to initiate change. As we read in a few cases, this change can be difficult.

Service System Lessons

Almost all of the projects represented here established some form of referral system, interagency linkage or integration of services. After years of working with these systems they have been able to reflect on the process used to establish and maintain the networks and articulate a number of common lessons.

Establishing agreements

In order to minimize delay with implementation, it is advisable to establish fairly extensive agreements with potential partner agencies early in the process. Letters of support are inadequate. Rather, engage key agencies during the proposal development process ensuring that they share the belief that the need identified is a significant one, and that they understand and support the proposed intervention model. To avoid the time intensive aspects of developing new linkages, it is also advisable to work with agencies already well know to you and with whom linkages already exist. Be cautious when deciding to work with new agencies.

Network building

A primary component of successful linkages are the informal personal relationships that exist between staff at your agency and staff at the partner agencies. When preparing to develop linkages, identify the individual in your agency who can function as a network builder. This is usually the one person who focuses on developing relationships, who is well-known and respected in the community, and can function at both an executive and program level. This person may also need to have the capacity to work outside of the service field as you may be required to build linkages with non-service provider institutions. These institutions will have different missions and philosophies—it will take care and respect to build working relationships. This issue is most apparent for projects working in prison systems.

Explicit agreements

It is critical that all partner agencies are clear about and support the goals and objectives of the project. Likewise, any agreements need to be very clear. If a linkage agreement involves compensation from you to the partner agencies, the protocols for delivering the compensation and the services expected in return should be precisely defined. It is worth reviewing the agreements regularly in order to confirm a common understanding of their terms.

Maintaining systems

Relationship have to built at each level of the systems and cannot be carried simply be agreements entered into at the executive level. A service system is only really in place when it is used by both line staff and clients. The flow of clients in particular cements the system and plays a critical role in its ongoing development. Line staff in each partner agency largely determine whether clients enter the system and how they move through it. Line staff usually only work with staff in other agencies if they feel comfortable with them and have confidence in the services the other agency provides.

Once a system is operational, it will need to be maintained. This requires regular coordination of inter-agency linkages, ongoing provider training, and cultivating good working relationships with front-line service staff at network agencies

Co-location rather than referrals

Finally, when working with marginalized populations, it may not be possible to identify a partner agency that has the capacity to deliver the services in a manner this is going to be effective for the clients. Some services may just need to be located in-house. A potential model for achieving this is to enter into linkage agreements with other agencies where it is the staff at those agencies rather than the clients who travel through the system. Skilled staff from a number of agencies can be located in the same facility and function together as a service delivery team while maintaining strong relationships with their home agencies.

Staffing Lessons

The more complex the needs of the clients, the more complex the service environment will need to be. A multidisciplinary team of providers is required to develop a diverse service system. Having talented, dedicated staff that work well with clients is one of the surest guarantees of success. It is also one of the more difficult things to provide, especially when funds are limited. Many of these projects describe using service delivery teams and provide lessons on how to develop and maintain them.

Recruiting and keeping staff

A good working environment and adequate compensation are necessary to recruit and maintain a well-functioning team of professionals. Professionalism, respect and a sense of common purpose or ownership of the project is also critical. Many people choose to work in this field because of a community ethic. If this is frustrated the morale of the workers and consequently the service environment will drop. Supervisors and managers can influence the character of the working environment and should pay attention to how she or he goes about doing this.

Staff development

Neither service environments, clients nor staff are homogeneous. Team members come from different professional backgrounds and bring with them different philosophies, goals, and professional relationships. The increasing need to mix highly trained and peer workers is adding greater range to this professional diversity. Building teams out of individuals with different personalities and experiences requires regular opportunities to discuss process, clarify difference and build relationships. The time devoted to staff development runs counter to the trend toward increased productivity, particularly on the part of medical care providers. Managerial and executive staff will need to weigh the costs of staff development time against the benefits that come from the general elevation of skills when provider teams are able to share experiences and skills.

Working with peers

Using peers is very useful in engaging clients. The use of peers does, however, require close ongoing and, often immediate professional supervision. Given their proximity to the client population, peers need assistance negotiating boundary issues and ensuring adherence to the program philosophy. Peers also need to be encouraged to adopt a non-judgmental approach to program clients. In addition, peers have ongoing service needs of their own and are subject to burn-out and relapse in a way that other staff are not. It is essential that their needs not be neglected.

Resolving conflict

While multi-disciplinary teams bring great strengths to the program, they can also be plagued by conflict. Strategies for avoiding conflict are to ensure clear roles, specialized training, and maintaining open communication between team members under the guidance of a skilled supervisor. It is also important that the team function as a team. Do not concentrate caseloads exclusively with one person. A client may be assigned a primary case manager but that case manager should not, alone, be responsible for the well-being of the client. This reduces the possibility of burn-out.

Staff turn-over

Staff turn-over is one of the most frequently cited reasons for delays in progress. This is especially the case when working across service settings on complex shared protocols. If staff leave, try and build in a process whereby the departing staff member can work with the incoming employee and provide foundational training.

To assist with training it is also valuable to document procedures and key learning issues. Such an archive is an important resource for incoming staff.

Client Lessons

Multiply diagnosed persons often behave in ways which challenge the patience of staff, program administrators, and even other clients with whom they interact. The wariness of providers is mirrored in the distrust clients feel toward the health system. These clients enter the program having had extensive institutional experience, little of it positive, and do not respond well to traditional service approaches. They are also known for high rates of non-adherence and recidivism. The lessons of the providers represented here focus on culturally appropriate care, a deep understanding of clients needs and processes, and the importance of engagement and stabilization.

Competence

To interact appropriately with clients, the majority of whom are not members of the dominant culture, requires skills that go beyond conventional notions of cultural competence. Some of the populations served by these providers are marginal to minority communities, living lives that place them outside of most established, protected and empowered social systems. Staff must understand what HIV/AIDS means to these clients and how their HIV infection and illnesses relate to their overall lives. One of the most basic elements of this understanding is an appreciation for the competing demands faced by clients. The requirements of daily living, for example, are likely to take precedence over medication start-up and adherence. Lives are lived in crisis and health issues are recognized when a crisis is experienced.

Competing demands

Needs assessments should reflect the demands of daily life. These competing demands are critical barriers to care and cannot be avoided by providers because they are beyond the agency's resources. Two areas of need that emerge strongly from the work in the projects, is the need for housing and mental health care. Housing instability is very high and a significant threat to being in care. Given the high level of stress experienced by these clients and the prevalence of traumatic histories, mental health issues have become an important focus for many of the providers in this collaboration. It is recommended that systemic screening of all patients for mental health needs be included in intake and follow-up procedures.

Engagement and stabilization

Disappointments are inevitable as clients "act out" to sabotage their recovery, relapse, or disengage from services, even after promising gains have been made. Seasoned providers describe a process of constant engagement and stabilization with clients. To first engage clients in care requires a lengthy period of low-level contacts before entering into more intensive services. It also means that programs relying on outreach to multi-problem populations may not see the fruits of that outreach for some time. Outreach may also need to be more intensive, ensuring repeated contacts with the same clients in order to build trust and facilitate the entry into treatment. Effective work with the hardest to serve requires seizing every opportunity for engagement. It also requires to ability to tolerate instability in the service relationship.

Additional Resources

Each of the projects profiled here has undertaken an evaluation of their intervention model. In addition they have contributed data to multi-site evaluation initiatives. The grant cycle for the interventions ends in September 2001 at which point the results of the evaluations of the individual models will be available, as will preliminary results from the multi-site effort. Where appropriate, these data will be used to update the Lessons Learned pieces. These revised pieces, along with other reports from the individual projects, will be available on the Health Services and Resource Administration's (HRSA) website at the following address: *http://hab.hrsa.gov/evaluation.html*

If you are interested in replicating all or part of models described here, you are encouraged to call on the individuals responsible for these projects and use them as a resource. At the end of each piece, the name and contact information for these individuals is provided. The knowledge they have far exceeds what is included in this document. They will also be able to help you applying the lessons laid out here to the particular issues you are facing in your service setting.

Acknowledgements

The pieces in the monograph were co-authored by staff from the twenty-five projects and members of the Evaluation and Technical Assistance Center (ETAC) at Columbia University's Mailman School of Public Health. ETAC is the coordinating center for the multi-site evaluation.

The monograph was edited by Robert Sember of Columbia University, Leonard Mitnick of the Special Projects of National Significance program, and the members of MediaWise, a media group located in Indianapolis specializing in health services information technology.

Canaan House Project, Catholic Community Services (Newark, N.J).

Developing Permanent Housing

Authors: Elizabeth K. Patterson, Elaine V. Cohen and Jo L. Sotheran

This illustrates the complexity and time requirements of combining an innovative program model with new construction or substantial renovation.

Introduction

Current approaches to funding and service delivery systems for end-of-life care have left huge gaps that force homeless, multiply diagnosed terminally ill people with AIDS to seek out fragmented services that are inappropriate and not cost effective. Often they must access multiple services while living in housing (often temporary or unstable) that does little if anything to facilitate utilization of vital services. In contrast, Canaan House provides permanent supportive housing for the multiply diagnosed, HIV-positive client in an apartment-type setting. It is a permanent supported independent living facility that will serve up to 10 residents in the Jersey City area.

The goal of the Canaan House Project is to help clients live in the community as independently as possible for as long as possible, by making it easier for them to use community-based medical and social services, adapting to their specific housing needs, and developing a socially supportive environment within the building and surrounding community.

During the past three years, the project has learned a number of instructive lessons on how to plan for the acquisition, rehabilitation and implementation of permanent housing for multiply diagnosed clients

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Among the many unmet needs of people with AIDS....none is felt more urgently than the need for permanent housing, especially for those with severe, persistent mental illness and/or addictions.

Location

Hudson County, centered in Jersey City, has the second-highest seroprevalence rate in the U.S., exceeded only by New York City, its immediate neighbor just across the Hudson River. Among the many unmet needs of people with AIDS in Hudson County, none is felt more urgently than the need for permanent housing. This is especially true for homeless people living with HIV/AIDS who are affected by severe, persistent mental illness and/or addictions, a need also identified by the Hudson County Ryan White Planning Group. The local situation is particularly difficult in light of the increased scarcity of affordable housing in the area, brought on by local redevelopment and economic growth.

Background

Catholic Community Services is the non-denominational social services agency sponsored by the Roman Catholic Archdiocese of Newark. It serves Hudson County and the three other counties that make up the Archdiocese with a wide variety of programs for individuals and families, carrying out the traditional role of the Catholic Church in serving the poor.

The existing continuum of care for Hudson County's homeless population includes St. Lucy's (a short-term shelter) and Franciska House (transitional housing). Canaan House will fill the gap and provide permanent housing. St. Martin de Porres House, an end-of-life residential facility is now in development under CCS' sponsorship.

Canaan House Model

CCS developed the model for Canaan House in response to a need for permanent housing perceived and expressed by clients in curreent case management, emergency shelter and transitional housing programs. A local needs assessment, involving service providers/clients in other local programs and in relevant planning bodies (i.e. Hudson County AIDS Task Force) confirmed that permanent housing was a client need. CCS also was motivated by the high rates of HIV in the metropolitan areas and by the need to provide HIV/AIDS clients with a continuum of HIV-related services including housing. The model conceived by CCS uses an urban apartment house setting to provide residents with:

- permanent, affordable housing with an individual lease and rent level based upon a percentage of documented income;

- related supportive services (such as client education, support groups, case management to facilitate links to other services);

- transportation to needed services and other activities;

- 24-hour, 7-day-a-week access to program staff/services.

Residents will live independently and have individual leases. Potential conflicts between residents' roles as social-service clients and as building tenants will be minimized by the use of "blended management." A program manager (in cooperation with a case-consultation team) will oversee the social-service aspects of the program and facilitate service linkages for tenants. A parallel building manager will be charged with maintaining the building in good working order, and a resident superintendent will have day-to-day responsibility for operations.

An existing apartment building was purchased and plans developed to renovate this building to provide eight one-bedroom units and one two-bedroom unit (with additional space being readied for future renovation of an additional three one-bedroom units).

Lessons Learned

The original development plan for this project anticipated that construction would be completed within one year of the grant award and full initiation of program services would commence within six months of completing the renovations. In reality, construction began some 30 months after the execution of the contract between HUD and CCS in January 1998 and program services will probably not start until the first quarter of 2001 at the earliest. While the overall program model did not change, adjustments had to be made to the building design and to the implementation schedule for the program due to:

1. Accommodate unforeseen delays and the funding and cash-flow issues that surround them;

2. Governmental administrative and fiscal requirements (such as accessibility, environmental review, zoning) familiar in the world of housing development, but largely outside the experience of social service providers such as CCS;

3. Local concerns about the project and convert initially adversarial relationships into constructive and supportive ones.

Lesson #1: Contingency planning is critical.

Under the best of circumstances, construction is time-consuming and subject to delays and unforeseen circumstances. Departures from the planned schedule in the Canaan House project have resulted from both these usual construction-related conditions such as unforeseen changes in regulations, and from the agency's unfamiliarity with codes and procedures. Canaan House has been able to ameliorate some of these problems by working with an existing housing developer, securing a construction bond in a timely manner, and seeking knowledge and assistance available within the agency and outside. A major lesson has been to be sure to build sufficient time into the project timetable if it involves new construction or renovations. Realistically, this could take at least three years from project conception to completion, especially if construction of permanent housing is planned.

These lengthy timetables can create additional problems if financial planning has not estimated delays into the process. This is particularly critical for many social service agencies, which do not possess funds to cover expenses until construction is completed and all reimbursement secured. Planning should reflect financial resources. Inflation or cost of living increases should be built into initial renovation/building estimates as fluctuations in the housing market, increased labor/materials costs and ongoing building deterioration (especially if renovations are delayed) will significantly increase costs. If possible, have a formal, long-term financing plan (that incorporates funding from several sources) in place to ensure renovation cost overruns are covered and that program services can be continued after the present funding expires.

Plan for resources to cover:

- delays
- inflation/cost of living
- increases
- increased labor
- increased/extra materials
- building deterioration

Lesson #2: Know the administrative requirements.

As social service providers move into becoming providers of specialized housing, they confront an unfamiliar world of planning, regulation, and financial constraints. Learning requirements in advance and attempting to plan around them can make navigating these requirements easier. Four that require particular attention are:

- Zoning. Investigate the zoning of proposed site up front. Selecting a building or a lot that already is zoned to allow the type of program you are developing can save a great deal of delay by avoiding an open hearing on re-zoning.

- Environmental review is required prior to renovations. CCS had trouble coordinating review and approval of the site environmental review between the regional HUD office and the municipality, who usually oversees these functions for its local HUD formula grantees. This caused a number of delays in the project. In the future, CCS would clarify the relative responsibilities with the regional HUD office at the start of the renovation planning process.

- HOPWA funding requirements. Investigate what is required by the HOPWA legislation. The regulations outline grantee obligations and program requirements for HOPWA recipients. CCS was able to build a number of these provisions into the project by reviewing this legislation in the initial planning stages of the project.

- Legal aspects. As housing rather than social services, projects often fall under the purview of local fair housing and anti-discrimination legislation. It is important to review this as early as possible so as to incorporate it into tenant selection processes.

Lesson #3: Develop community relations early.

HIV-related housing is not always welcomed enthusiastically by the surrounding neighborhood. Canaan House faced a substantial measure of community opposition early in the project. This opposition has been largely overcome with a concerted program of government and community outreach. Developing relationships early in the process is very important if the community is not to feel excluded and threatened by the proposed development. CCS would have reached out to the surrounding community earlier in the development process in an effort to offset some of the delays that resulted from the community opposition to the program. Developing relationships among not only the community, but also with local government officials/agencies, other providers and with surrounding clergy is vital in order to facilitate solutions to barriers that will be encountered in the development process.

Canaan House Chronology

November 1997

- CCS is formally awarded grant under the HOPWA competition program to begin development of Canaan House.

March 1998

- A program manager is appointed for the project.
- With the guidance of Catholic Community Services' housing development agency (Domus), a local architectural firm is retained to provide input and supervision to the renovation aspect of the project.
- As a preliminary to community outreach, staff meet with local council member representing the area where the project will be located to introduce her to the agency and enlist her assistance in establishing a community meeting.

April 1998

- A community meeting is held to familiarize the neighborhood with the Canaan House project. Although invitations were sent to local block associations, political/spiritual leaders in the city, notices were also sent to media and posted in local business establishments, attendance at the meeting is very low.

May 1998

- The project development team holds the first of many organizational meetings to discuss coordination of the various aspects of project development and planned building renovation.

- The project architect is contacted to schedule a review of the building, as preliminary to completing the environmental survey required by Jersey City building codes.

June 1998

- Architect completes walk through of the building, and the program manager outlines the program's service needs to aid the architect in the developing a work estimate and renovation plan.
- Staff from Evaluation and Technical Assistance Center (ETAC) at Columbia University have first meeting with Canaan House development staff. Reviewed draft of evaluation plan and begin work on linkages template, an instrument illustrating the service linkages in which Canaan House will participate.

July 1998

- Staff complete first version of linkages template.
- Development team and architect meet to discuss project and renovation schedule. Financial estimates cause consideration of alternative design options
- Delays occur in the separate environmental surveys required by Jersey City and the Department of Housing and Urban Development (HUD).

September 1998

- Evaluation of Canaan House project is reviewed by Catholic Community Services' Institutional Review Board (IRB) meeting. IRB suggests items for consent forms.
- Second visit by ETAC to address concerns about study structure and use of control groups.

October 1998

- Planning begins for admission to and management of Canaan House. This is a complicated issue, as each tenant will have an individual lease (as in most other housing) but the lease must allow for occasional absences for needed treatment. Contacts are made with other CCS housing programs to request copies of their leases for possible use at Canaan House. Staff also met with HIV/AIDS related housing projects of CCS to seek input on admission standards for Canaan House and explore ways to structure program to assure best chance of client success.
- Delays continue in environmental survey processes at both city and federal levels.
- Development team meets to discuss status of renovations and plan for next phase.

November 1998

- City of Jersey City completes the environmental survey of Canaan House under the direction of HUD and sends results to HUD regional office. This is some four months after process started, in July.
- Project development staff completes first draft of admission criteria as well as rough draft of the admission procedure. To ensure consistency with evaluation plans, ETAC staff review the documents during site visit. ETAC also further refines research plans and evaluation tools.

December 1998

- Program manager and CCS staff held meeting to review latest draft of research plan. Determine to use same core instruments as used by another CCS-sponsored HUD/HOPWA SPNS project, Operation Link. This coordination of instruments will contribute to comparability of client and outcome data across two different CCS-sponsored projects serving slightly different clienteles.
- Staff drafts and revises outline of program services; planning for services continues and conducts assessment of media needs for the new project such as client-recruitment advertising, community outreach, agency publicity, are among the needs considered.
- Program management staff meets with project architects for building review and drawings. It is now six months after the architect began work on the project.

January 1999

- ETAC evaluator submits draft evaluation plan to CCS staff, for review and revision.
- Staff and architect review preliminary design drawings, staff recommends adjustments based on program needs.
- In the first hint of community opposition a local clergy member, claiming to represent block association, voices concerns regarding the project.

February 1999

- Second community meeting held to address community concerns (primarily centered around property values and neighborhood quality of life issues) raised at the previous meeting in January 1999. Participants agree to form a committee to study the matter further and continue dialogue.
- Project staff met with representative from a supportive housing agency to discuss how the organization could supply technical assistance to the project. The agency will assist in development of the lease, comment on development of program services portion of the project. It also agrees to provide additional materials for use in the development and implementation of the program model.

March 1999

- Site visit by ETAC leads to further refinement of evaluation plan and evaluation tools.
- Relations with community appear to be deteriorating. CCS learns of meeting scheduled by local clergy member and his block association to which CCS is not invited. Despite numerous attempts by CCS staff, CCS is unable to schedule follow-up committee meeting as agreed at the previous month's community meeting.

April 1999

- Community committee chair calls program manager and advises CCS that the committee is not needed since the Canaan House project is not wanted in the community at all. CCS begins to enlist support from other neighborhood organizations, contacts various city agencies to discuss project and possible sources of support.
- Supportive housing agency provides legal assistance to CCS staff, as requested. Aspects of leasing and tenancy are finally clarified.
- Staff completes and sends annual progress report to local and national HUD offices.
- Architects finish final drawings and send them to the project developer for review.
- Delays in bidding process for construction services begin to result from continued delays in HUD's confirmation of its review of environmental survey.

June 1999

- Program development team met to continue planning, met with ETAC evaluator to continue work on evaluation tools.
- Staff meets with city housing office regarding recent community opposition and strategies for addressing it.
- Project staff met with community leaders opposing program to continue the dialogue begun in February.
- Issues regarding the preliminary environmental review and HUD are finally resolved. CCS' housing developer accepts and begins to implement proposal for the required Phase II of the environmental review of the program site.

July 1999

- Program development team meets to discuss revised building schedule and its affects on finances and programming, and meets with evaluator to re-define evaluation plan based on new projected timeline for renovation.

- Staff is alerted by the city housing office of a new plan to redevelop vacant city properties. This will require additional city review of Canaan House building plans.

August 1999

- CCS Finance Department and building developer start working with local and federal HUD offices to set up draw down procedure so grant funds can be accessed for renovation costs. Funds available for up-front costs from parent agency (CCS) are very limited.
- Architect files for construction permit and begins working on bid package to choose general contractor.
- Potential membership list for a Program Advisory Committee (PAC) is compiled in response to recommendation made by community leaders at June 1999 meeting. Staff hopes to tap into several segments of the community to create dialogue and generate local support for the project, itself located in a neighborhood affected by drug use and HIV.

September 1999

- Draw down procedure established with HUD, allowing the program to start expending funds in advance of actually opening.
- Staff updates the CCS advisory board on status of Canaan House program; two Advisory Board members with other local affiliations volunteer to serve on PAC.
- Construction can finally start. Phase II environmental review is completed by the environmental consultant. Jersey City approves building plans submitted for project. Based on these prerequisites, architect completes bid package to be sent to potential general contractors in early October.
- Canaan House program manager discusses the Canaan House program with a documentary film crew chronicling the Catholic response to the AIDS epidemic.
- Dissemination plan completed, focusing on small local media needs.

October 1999

- Development team meeting held to set up procedure and timeline for submission and selection of bids from general contractors.
- Staff mail compile list of 90 community members, mail letters inviting them to apply for membership on the PAC. To further community support, staff meet with local police precinct to introduce them to the program and to enlist their support/assistance.
- Staff attends ETAC meeting held in NY to work on concept paper addressing housing readiness issues among the target client population.
- Draft typology completed by ETAC evaluator in collaboration with CCS staff.

November 1999

- Canaan House program manager participates in the SPNS/HOPWA Institute Day at the US Conference on AIDS in Denver, CO.
- Staff begins first round of interviews for PAC membership.
- The bidding process continues. Bid submission period is extended by several weeks to allow contractors additional time to respond. At end of November, bids are opened and reviewed by the program development team. More detailed proposals are requested from two local general contractors.
- Staff meets with new ETAC evaluator of program as original evaluator moves on to other projects.

December 1999

- Program manager meets with CCS Finance Department to discuss long term financing of program, which is still not clear. This information will be presented to development team during its January meeting.

- Staff receives revised bids from one of the two contractors contacted, and requested additional clarification of labor costs on this bid.

January 2000

- Received revised labor costs as requested. Rapidly rising local labor costs and delays in the bidding process require revisions of cost estimates.

- Canaan House program manager presented at a housing seminar during Ryan White Cross Title meeting in Washington, DC.

- Staff joins the research committee for Supportive Housing Association of NJ (local arm of CSH), as a further source of program and legal guidance.

February 2000

- The development team meets to formally select the general contractor and bid package. Long-term funding strategies are also discussed at this meeting.

- Architect and CCS Legal Department begin preparing construction contract for submission to the selected general contractor.

- Canaan House program manager and other CCS staff are invited to present seminar on "AIDS Housing" at First Annual NJ Catholic Charities Conference in May and to present on the program and the SPNS initiative to a committee of the CCS Board of Trustees in April.

- Staff continues work on community relationships, contacting and interviewing local consumers interested in PAC membership.

March 2000

- Staff finalizes PAC membership list, sets a first meeting for mid-April.

- Negotiated and executed final contract with general contractor with start date for renovations being set for mid-April, 2000; bid prices locked in.

- CCS applies for construction bond necessary for final construction completion.

- Project staff meets with CSH to discuss additional financing sources on state/local levels to replace the current federal start-up funding, and to start planning a state-wide research initiative on supportive housing in New Jersey.

April 2000

- First meeting of the PAC is held. Staff is able to allay many community concerns, receives valuable input from community members present.

- CCS finalizes contract with the project's general contractor.

- Canaan House staff attend the 9th PSC meeting in San Francisco, CA, are able to share what is now their expertise with other PSC members at earlier stages of project development.

June 2000

- As required by local legislation, notice regarding the renovations and the environmental survey is published in the Jersey Journal, local newspaper of record.

- Second PAC meeting is held.

- More than two years after grant award, recruitment for potential tenants can finally begin. Staff begin outreach to local area HIV/AIDS case management agencies (Jersey City Medical Center; FAITH Services; Christ Hospital Home Healthcare; Horizon Healthcare & CCS MICA Outreach) to inform them about program and to get input into client/agency needs.

- Canaan House staff and the program evaluator continue to discuss local evaluation questions and objectives.

- Renovation of the program site, first planned in March 1998, finally starts.

July 2000

- Jersey City's Building Department temporarily halts renovations in order to review the renovation plan for compliance with accessibility regulations in the new State building code. In the interim, work progresses on excavation and environmental remediation at the program site.

- The Canaan House renovation plan is revised to accommodate recommendations by Jersey City Building Department for new dimensions for the entrance ramp,, reconfiguration of the new elevator, and layout of program units to promote greater unit accessibility for residents. Program director and program developer visit renovations at program site.

- Program director contacts the local HUD office in Newark for guidance on applying for the no-cost contract extension required by the numerous delays.

August 2000

- Redesign to accommodate accessibility issues is completed and renovations are resumed, with only a one-month delay for redesign.

- Third PAC meeting is held.

- CCS' Building Development team reviews building to assess and plan for in-house services (such as MIS, telephone, site safety, etc.).

- Revision of Canaan House multi-site and local evaluation plan continues, a qualitative component is added to compensate for the difficulty anticipated in completing the follow-up standardized interviews originally planned.

- The program director and program developer visit renovations at program site; current estimates given by general contractor put completion of renovations at late December 2000/January 2001, almost three years after the initial grant award.

September 2000

- Canaan House participates in the "Facts from the Frontline" presentation to HUD in Washington, DC. The presentation includes photos of site and renovation to illustrate the difficulties of new construction or major renovation.

- Canaan staff, in conjunction with the program evaluator, completes work on the Canaan House multi-site and local evaluation tool/plan. These will be submitted to the CCS Institutional Review Board (IRB) for their review and comments at their October meeting.

- Renovation work continues on program site.

- CCS submits a no-cost extension request (asking that its contract with HUD be extended through Sept. 2002) to the Newark-HUD Community Development office.

October 2000

- Fourth PAC meeting is held. Staff hope that this ongoing contact with community members will help create a supportive neighborhood environment for the future residents of the project.

- Application made to the city of Jersey City for HOPWA formula (non-SPNS) funds to cover development of an additional three apartments at the Canaan House site. This will help compensate for the units lost earlier when increases in construction costs required a decrease in the number of units built.

- Canaan House multi-site and local evaluation materials are submitted to the CCS IRB for their comment and approval.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by Canaan House you are welcome to contact the project director and request technical assistance:

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3040 Kennedy Blvd.
Jersey City, NJ 07306
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Positive Match Program, Bernal Heights Neighborhood Center

Housing and Services for Multiply Diagnosed Women and Their Children

Author: Kathleen Manthe and Jo Phelan

Introduction

Positive Match was created to meet the needs of homeless and marginally housed HIV-positive single mothers and their children. Housing for women with HIV disease is extremely limited in San Francisco, especially multiple-bedroom units needed by families. Tenant-rental assistance certificates, for which families targeted by this program are eligible, are not practical because they do not provide enough money to pay for the units that are available. There is a great deal of competition for any available low-cost housing. Project-based housing developments have long, multi-year waiting lists, and the application and eligibility requirements present severe obstacles. Also, fragmentation and poor coordination characterize the current service delivery system for HIV-affected families in the city. Many of these women have histories of substance abuse and mental health conditions as well as HIV disease. The majority have active substance abuse issues and histories of family violence. Therefore, many of these women need intensive service intervention. Using models of community support and home-based service delivery, the program strives to minimize barriers to housing and services that these women often confront. The program encompasses service delivery, housing advocacy and education, providing a full continuum of care for this population.

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Over the past four-and-a-half years, the program has learned a number of instructive lessons on how to secure housing, deal with community resistance and provide services to these families. A brief overview of the project as well as some of these lessons are highlighted here.

Location

The program is located in San Francisco, California. San Francisco has an extremely tight affordable-housing market. Vacancy rates for rental housing hover at less than one percent citywide.

The ideal building would contain four to eight multi-bedroom units, each for one family, and would also house family activities and supportive services. Setting a lower limit on the size were economies of scale and the desire to create an opportunity for a community of support to develop among clients. Bringing together several families and services in one building provides an economy of scale for services costs and makes services very accessible for the families living there. Setting an upper limit on the size of the building were cost and visibility. A larger building was not ideal because the cost would be excessive in relation to available funding streams, although even smaller buildings exceeded available funding. Also, because of the possibility of negative community reaction, an unobtrusive presence was desired. Based in part on the input of client families, the ideal location for the site was envisioned as being in a family-oriented neighborhood, on a low-traffic street, in an unobtrusive location and building, near a major medical center, within walking distance to schools, having access to public transportation, a grocery store, recreational facilities for children and would have disability access. The Western Addition area of San Francisco met these criteria and was well-suited to this particular client group, because many had lived in the area before and had family living there.

Services

Positive Match Program was designed to have the following components: Permanent supportive housing for a small number of families (four to eight) and comprehensive case management for approximately sixty

The Bernal Heights Housing Program Logic Model

The program was designed to provide permanent supportive housing for four to eight families and comprehensive case management for approximately 60 additional families.

Problem

Impact of HIV on poor families with many multigenerational problems

Need

- Discrimination
- Inadequate services
- Housing instability
- Parental loss

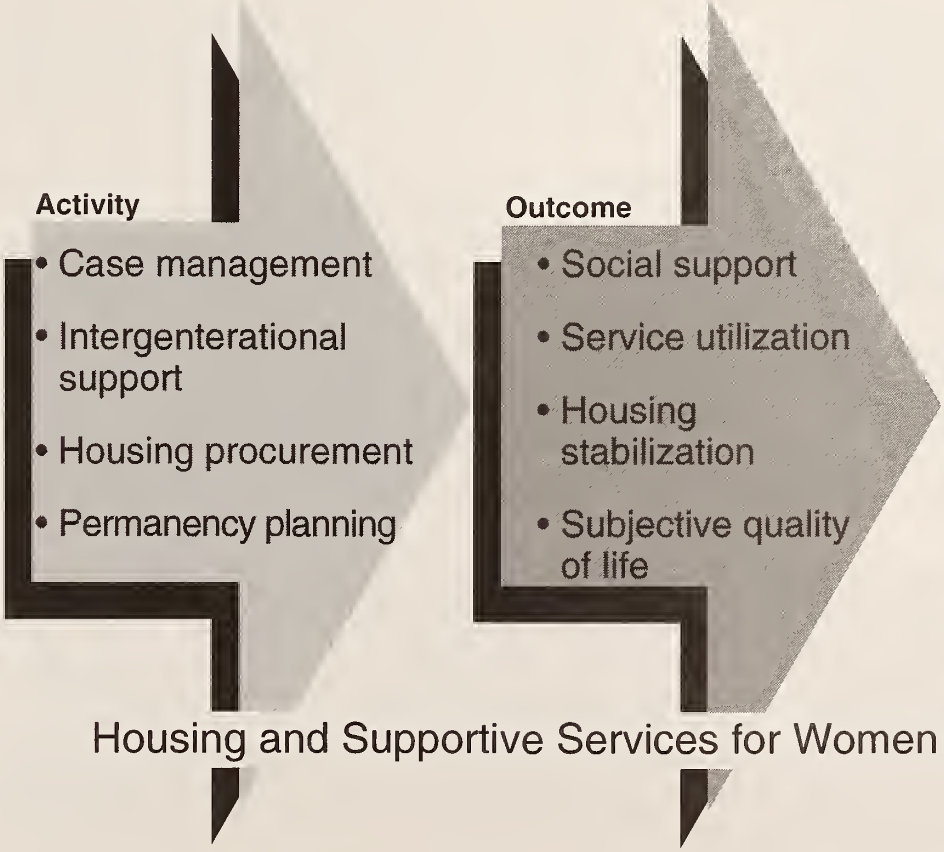
additional families with a focus on linkages with emergency and long term housing. For all families, the program was designed to provide intensive case management services to support linkages to housing and supportive services, integrated substance abuse and mental health services, permanency planning for children, and aftercare for children and guardians. A comprehensive outreach and educational component was also planned. The program was designed with a child-centered, family-support model for home-based service delivery that emphasizes early intervention, flexible individualized services, parent education and the development of supportive networks. The underlying rationale for the intervention package was a model of community support. Families living in the property, as well as those who lived elsewhere but gathered for social and other activities, would develop a peer-based network that would in some ways serve as an extended family. Families could draw on one another for help and share knowledge and resources. This network could help mothers care for children when they are ill or busy. This network would reduce exposure to and feelings of stigma and enhance self-esteem. This supportive community is the central component of the program. Providers would be part of this extended community and not seen as distant or sterile.

Lessons Learned:

Lesson #1: Collaborate.

Implementing this program depended upon the collaboration of housing and service providers. This was an innovative aspect of this program and brought challenges with it that could not be foreseen. The two kinds of providers have complementary types of expertise and experience and both are strongly motivated to help clients, however, they also bring to the table different sets of priorities and values that must be integrated.

One prominent example of differing priorities is the conflict over allocation of funds – how much of a limited supply of money should be allocated for housing, how much for services? Another example has to do with different needs and perspectives related to the role of landlord vs. that of service provider. For example, in a situation in which a client stops paying the rent, the services provider might be more concerned with



Activity

- Case management
- Intergenterational support
- Housing procurement
- Permanency planning

Outcome

- Social support
- Service utilization
- Housing stabilization
- Subjective quality of life

The underlying intervention rationale is a model of community support. Families develop a peer-based network that serves as an extended family. This community is the central program component.

Housing and Supportive Services for Women and their Children

Discuss program design and components, as well as goals, values and priorities among all collaborators from the beginning of the proposal stage.

understanding the problems the client is confronting, while the housing provider must be concerned with getting the rent. In this collaboration, the decision hierarchy became unclear at some points. In the case of funding from this particular source, evaluation of the program's effectiveness would be based on client outcomes. This added weight to the services side of the equation.

It is important to discuss program design and components, as well as goals, values and priorities among all collaborators from the beginning of the proposal stage. There should be important input from all key collaborators at the stage of writing the proposal, since the proposal, if funded, will determine what must be delivered. Feasibility and coordination of goals should be carefully laid out at the proposal stage. Agreements and compromises should be worked out at that stage. Even with careful planning, it should be recognized that differences will inevitably arise.

The original funded collaborators were Catholic Charities, with experience in services delivery and Housing Services Affiliate (HSA) of the Bernal Heights Neighborhood Center, with experience in housing rehabilitation and acquisition, especially small-scale supportive housing. There were also important non-funded collaborators that would provide medical and social services. The involvement of the San Francisco Redevelopment Agency was important in recognizing the need for supportive housing for the population to be served and helping to secure funds and technical assistance. Technical assistance was initially provided by the Corporation for Supportive Housing. At a later point, AIDS Housing of Washington was also asked to and provided technical assistance. Because the two technical assistance groups had conflicting philosophies and visions regarding some issues, it became difficult to decide how to proceed. The involvement of the latter group was eventually terminated, and with a more unified approach to technical assistance, progress was facilitated.

Lesson #2: Consider any possible alternatives.

San Francisco is one of the most expensive cities in the country. There is a limited stock of housing and a very limited stock of larger family-sized units. (Sixty percent of rental units have one or fewer bedrooms). Gentrification resulting in part from the growth of nearby Silicon Valley reduced the stock of low-cost housing. Certain low-cost areas of the city were not appropriate for housing families because of safety problems and exposure to drug dealing, etc. Because of the tightness of the San Francisco real estate market, there are policies tied to public funding prohibiting the purchase of a building that will result in displacing current occupants. Housing families outside the city was not a good option, because the available services would be inadequate. The plan called for a mixed-use building (housing and services), adding additional limitations on available sites imposed by zoning restrictions. Finally, the HOPWA award was reduced from the requested $1,200,000 to $845,000, requiring extensive additional fundraising by the main collaborators.

Before the grant was funded, an appropriate and affordable site had been identified. However, an unanticipated, unnoticed zoning problem (multiple use, i.e., combined housing and service provision, was not allowed) made that site unsuitable. The search for an alternative site was further impeded by the fact that housing prices in San Francisco were rising. Competing for available housing was made more difficult by funding agency requirements. For example, the environmental review process killed many potential deals. A long (six month) escrow was required, and there was the risk that the building would not be approved. In the tight housing market, this was a serious disincentive for potential sellers. To illustrate the extreme difficulty of the situation, 62 properties were researched for this project and offers made on eight properties in a 20-month period. As the eventually successful, but sometimes seemingly hopeless, search for a site continued, the collaborators considered alternative solutions.

Change the program model
When considering changing the program model the following possibilities were developed:

- A separate services center that would also accommodate play/social activities (This was the primary fall-back plan.).
- Scattered site housing - two or three separate two-to-three unit buildings with a separate service site.
- One housing and services site providing services only for those living at the site.
- Master leasing a residential space. There were several drawbacks to this plan: The agency does not control the unit and might eventually lose the use of the site. The agency has liability and because the site is not permanently acquired, some primary sources of capital funding are not available. Also, master lease situations are at least as difficult to find as multi-unit vacant buildings for sale.

Cover the carrying costs for potential sellers and apply for additional funds for both housing and services
Applying for additional funds proved to be critical to enacting the program as originally planned but entailed additional complications. The program collaborators sought non-traditional sources of funding for HIV populations. Applications were made to the McKinney super-NOFA, private foundations focusing on families (such as the Gellert Foundation and Tides Foundation) and HOPWA formula funds for capital costs.

Non-traditional sources can bring difficulties with them. For example, preparation of the McKinney proposal was time consuming and brought the group into competition with traditional homeless service providers. There was some sentiment that the Positive Match Program was seeking funds in a territory that was not appropriate for its clients and that the program should rely on HIV-specific funds. The program, which provides intensive case management and services, was challenged for being expensive for the number of clients served.

The blending of multiple funding streams itself also brings complexities with it. Different funding sources have different criteria and requirements. Multiple applications and varying reporting structures (which are not coordinated) create additional administrative burden. Sometimes agencies have competing priorities.

HOPWA/SPNS funds are extremely flexible. However, because the funds requested from this program were cut, additional funding sources with greater restrictions had to be sought. For example, utilization of Redevelopment Agency money meant that the building needed to be approved by a number of internal departments as well as approved by the Redevelopment Agency Commission which in turn depended on community input. Also, the program was originally designed to house-doubled up and marginally-housed people as well as literally homeless. However, The McKinney definition of homeless is more restrictive and did not allow this. This definition does not capture many families for whom services would be beneficial.

> Two to three years is the shortest possible time frame to develop a housing site.

Despite these obstacles, the application for McKinney money was successful; approximately one million additional dollars were secured. Also, federal HUD funds (specifically, Section 8 Project-Based Certificates) were secured — $650,000 for services and $400,000 for capital costs. These funds for the seven permanent housing units were secured for operating costs for the acquired housing and services site for 15 years. At this time, the biggest challenge is in securing ongoing funds for the provision of services.

The program learned that it was important to anticipate delays and realize that delays will increase costs. Housing acquisition and modification takes a lot of time. Service providers are less familiar with this situation and need to be made aware of it. Two to three years is the shortest possible time frame to develop a housing site.

Lesson #3: Prepare for community resistance.
Eventually, a site was found and purchased but there was community resistance almost from the moment that the purchase agreement became known. Some resistance was due to circumstances particular to this site and the agencies involved, other opposition was more general.

The site is located in a predominantly African-American neighborhood, and was a mortuary with a long history in this community. Several years earlier the long-time owner had sold to another owner who maintained the mortuary business. This seller put the building on the market, on a multiple-listing service. However, the seller did not take steps to notify the community of the intent to sell. A city-wide advocacy group with ties to this community claimed that the property had been promised to them.

While many of the Positive Match clients would be African American, most of the agency and program staff are not. Also, the Redevelopment Agency had a negative image in the neighborhood, because of an urban renewal program in the 1970s that displaced many residents and broke up the economically diverse neighborhood. There was a perception of a conspiracy to sell the property to an outside group behind the backs of local people who had a right to buy the property.

> Opposition also centered on the fact that clients would be HIV positive. The program was referred to as a "house of death."

There was also a perception that there was an over-saturation of AIDS housing in the area, and some residents felt that their community had become a dumping ground for programs that no one else wanted located in their neighborhoods. Opposition also centered on the fact that clients would be HIV-positive. The program was referred to as a "house of death:" there was fear of having the client children come in contact with neighborhood children, there was fear that disease would infect the neighborhood through water or sewage.

These problems were exacerbated by the fact that, because of the extreme difficulty in locating an appropriate site, the search took the Housing Services Affiliate (HSA) outside the area of the city it was familiar with and which was familiar with it. There was less knowledge on HSA's part about potential sources of difficulty, and there was less trust on the part of the community.

The purchase contract was signed in November of 1997. Opposition arose as soon as information about the sale circulated. Opposition was fairly organized and spearheaded by the aforementioned advocacy group, which expressed a desire to acquire the property itself. Opposition took the form of picketing, physical threats, and verbal harassment in public community meetings. Most opposition was directed at Catholic Charities and HSA and was informed by a lack of trust in the Redevelopment Agency. Opposition by community groups and individuals was fueled by the misconception that the SPNS funds could be withdrawn from this collaborative and reallocated to another agency.

From January to April 1998, meetings were held between the collaborators and opposing community groups, and the proposed use of the building was presented at a SFRA community meeting, open to the public. On the day of this hearing, opponents to the sale spoke to the mayor who implicitly supported this project by saying it was not his right to interfere in a private sale. At the SFRA commission hearing for funding approval for HOPWA, held in April of 1998 and attended by hundreds of people, a small but organized contingent of people aimed to disrupt the meeting with shouting, inflammatory comments, personal threats, and heckling. However, no physical harm was done, and the funding was approved that night by a vote of 4 to 3. Since that night, there has been no more visible organized opposition. However, the site is not yet operational.

Response to community resistance
In addition to the meetings, an intense effort was mounted to organize against opposition to the program and to

try to determine the overall community opinion. It was felt that if the community as a whole was opposed to the site perhaps another location should be sought.

Outreach, including meetings and petitions, was addressed to local public health centers, child-care centers, hospitals, churches and community leaders. Outreach to churches included numerous meetings with clergy and congregations.

Outreach to the public was also conducted at a local supermarket near the proposed site on an ongoing basis on Sundays where local residents could be found after church. This outreach included talking to residents about the proposed project, answering questions and getting their feedback, distributing brochures about the program and information on women with HIV and their housing needs, and distributing a petition and pre-formatted letters of support that residents could send to the SFRA Commissioners. Mass leafleting of local housing projects was also conducted.

As a result of these efforts, more than 900 signatures were obtained on petitions, and the SFRA Commissioner received a few hundred letters supporting the program.

Lesson #4: Extensive services need a secure home.

In general terms, implementation of the service components of this program was impeded by the difficulties regarding acquisition of a housing site. If the housing component of the program could not be implemented, it was possible that HUD would not fund the service components. Therefore, until it was firmly established that a site would be found and occupied, collaborators did not feel that it was prudent to draw down the HUD/HOPWA funds. For this reason, between September 1996 and August 1997, the service components of the program were provided by a skeletal staff to a limited number of clients. In December 1997, additional money was awarded from McKinney funds, which would make it possible to acquire an appropriate housing site. At this point, collaborators felt secure enough that the housing component of the HUD/HOPWA project was feasible and that money for services could be drawn from the HUD/HOPWA award.

Whereas the collaboration between service and housing providers was forged for the purpose of carrying out the program described here and developed concomitantly with the proposal for this project, the various service components of the program were coordinated among a group of providers who had long-standing collaborative relationships.

Recommendations regarding service provision

1. Drawing on established relationships between cooperative agencies with compatible philosophies greatly facilitates the effective provision of services to clients.

2. Recreational activities and sharing meals have seemed key to creating an atmosphere that is attractive to clients — both parents and children. When there are fun things happening, clients want to come and take part. These activities also provide a context in which interpersonal relationships and social support can grow naturally. When staff and clients share these activities, parents have an opportunity to observe how staff interacts with children and adults in social settings; this modeling allows clients to learn more effective ways of behaving.

3. For clients such as those served by this program, with multiple disabilities and life difficulties, and in a geographic and service context like San Francisco's, the provision of transportation and home-based services are key. Transportation is coordinated to all services and recreational activities and provides services at the client's home when necessary. Without this support, clients simply would not get the services they need.

4. Group art therapy has proved very effective with the children. Art projects provide a way to express feelings that might be difficult to express directly and verbally. At the same time, kids can express feelings about their art and what it means to the extent that they feel comfortable about it. They might talk about their feelings – they don't have to.

5. Permanency planning proved difficult and did not develop quite as expected. One lesson was that it must proceed very slowly. Facing one's own death and the giving up and taking of responsibility for another persons' life are very weighty issues and require much time to work through. It can't be approached aggressively. However, even if the process does not reach the point of identifying a guardian and making a legal agreement, any progress that has been made in terms of thinking about and having conversations with potential guardians is helpful if the parent does die. A further difficulty with permanency planning is the difficulty, in many cases, of identifying a family member whom the parent would trust as a legal guardian.

6. Money management was a voluntary program that required clients to deposit income in an account that was managed by a case manager. This program component was judged to be critical to keeping clients housed.

7. Medical services were provided by University of California at San Francisco Medical Center. The fact that it is a major, non-specialized medical center able to coordinate HIV, women's and children's specialty clinics and general medical care, was considered very beneficial.

Bernal Heights, Positive Match, Project Chronology

November 1995

- Formal discussions initiated between Rita da Cascia/ Catholic Charities (RDC/CCASF), UCSF Medical Center, Legal Services for Children/HOPE Project (LSC) in relation to unmet housing and service needs for multiply diagnosed women with children in San Francisco County.

February 1996

- HOPWA SPNS RFP released. Meeting at San Francisco Redevelopment Agency (SFRA) to discuss proposal. Bernal Heights Housing Corporation (BHNC) and CCASF are both attendees.

March 1996

- Discussion and refinement of model based on input from consumers. Bernal Heights Housing Corporation CCASF with Legal Services for Children, Edgewood Children and Family Center agree to formally collaborate to expand service delivery. Agreement to pursue harm reduction model with on-site service component in housing.

April 1996

- First housing site identified.

May 1996

- Application receives city approval and is submitted to HOPWA/SPNS.

July 1996

- Catholic Charities submits application to the Gellert Foundation for additional service funding.

August 1996

- The Project is granted funding through the HOPWA MDI grant. Project is funded at $845,000 which is more than $400,000 less than original request. RDC/CCASF and Legal Services for Children initiate discussions regarding additional funding options to fully implement the service model.
- Project accepts the first SPNS client for supportive services.

September 1996

- CCASF accepts two additional referrals for SPNS service component in keeping with the original project timeline.

October 1996

- Collaborating organizations meet with the San Francisco Planning Department to discuss building permits and zoning of property. Planning department states that zoning of property (RH1) will not accommodate a service model that provides services to families housed off-site. Services could therefore only be provided for individuals housed on-site at the facility. Due to residential nature of the area, the planning department indicates the project is unlikely to obtain a zoning variance.

November 1996

- Final determination follows discussion with all collaborators that property is not viable for the SPNS Project due to zoning issues.

December 1996

- Program continues to accept referrals and provide services for project participants. Discussion with current participants regarding the original model of service and design of permanent housing component. Women continue to support model with on-site services.

March 1997

- Original project manager for resigns and is replaced.

May 1997

- Site search continues.

June 1997

- SPNS grant agreement with HUD signed. Project applies for $50,000 more for evaluation component as required by HUD.

August 1997

- The project hires a case manager and direct service advocate to assist in implementation of project operations.

October 1997

- The Positive Match project is granted $50,000 from HUD for evaluation of the program.

- Property acquisition efforts continue. The realtor identifies a permanent housing site. The potential site is an operating mortuary that is zoned as a mixed-use site, allowing both residential and commercial use. The site is located in the center of low-income housing developments. Collaborating agencies jointly view the site on October 31, 1997.

November 1997

- One program partner enters into escrow to purchase the mixed-use two-unit building for $595,000. Bids are solicited from several consultants to conduct a Phase I environmental site assessment and lead based paint testing study. The collaborative determines that if cost estimates are viable, the property could be remodeled into 3-4 units with the possibility of construction of new apartments adjacent to the existing building. The building could also accommodate on-site supportive service space and offices for the staff.

December 1997

- The city redevelopment agency visits the site and relates that the building appears to meet their parameters. Some neighbors feel that they should have had an opportunity to purchase the building for other uses and are angry. Residents are contacted via telephone to discuss the project. The project staff receives an invitation to attend a local board meeting.

- The project is granted SHP/ McKinney funding of $1 million, $400,000 is dedicated for building acquisition.

March 1998

- CCASF, UCSF Medical Center and the Center for Special Problems submit a joint proposal for Ryan White CARE Act Title I funds to expand the service continuum of the project. Service expansion includes additional services for children living with HIV and a peer advocacy component.

- The project continues to be fully enrolled for services. All families originally placed in housing have maintained their permanent housing placement.

August 1998

- Following a review of more than 100 properties, a leased service site is identified. It will be used while the other facility is in development.

September 1998

- Joint children and mothers support groups are initiated. The groups are fully enrolled.

October 1998-May 1999

- Project continues to deal with inspection and rehabilitation issues. Services continue.

June 1999

- The third cycle of twelve-week groups for children and mothers with HIV is completed.

July 1999

- Cost estimates for the facility under development are reviewed. Costs exceed the current budget by $100,000 to $150,000. The cost difference is based on the differences between the two designs under consideration. The schematic design is revisited. Significant cost savings is incurred based on the early identification of these concerns.

- Services are initiated to relative caretakers and children of program participants. Referrals are made to the Black Coalition on AIDS for treatment advocacy services.

- The fourth session of groups for mothers and children with HIV are initiated. The provision of the activities program continues to expand.

August 1999

- Possibilities for other rental subsidies are investigated. The architects complete the revised design.

September 1999

- Open house at leased service site to celebrate Positive Match.

November 1999

- Program participates in panel as part of housing track at the US Conference on AIDS in Denver Colorado. Abstract involving Catholic Community Services in New Jersey, and Cambda in New York City is accepted for the Ryan White Title I conference in January of 2000.

Further Information and Technical Assistance

Should you wish to obtain additional information bout the service delivery model developed by the Postive Match Program you are welcome to contact the project director and request technical assistance:

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The Bridge Project, Lutheran Social Services

Housing for Multiply Diagnosed Men and Women with AIDS

Authors: Mary Gee, Gail Gilman, Davis Ja, Andrew Wicker and Robert Sember

This article chronicles some of the lessons learned from the Bridge Project, a SPNS- and HOPWA-funded program developed by Lutheran Social Services of Northern California. The information is based on interim findings from the first three-and-a-half years of a five-year demonstration project. Final results of the evaluation will be available upon completion of the grant cycle in Fall 2001.

Introduction

Homeless, chemically dependent, HIV-positive individuals who also have mental health problems are considered among the most difficult populations to serve. The Bridge Project has developed an innovative service delivery model for providing transitional housing, primary medical and mental health care, and supportive services to just such a population. The model relies on an interdisciplinary team of providers, close collaborations with service providers and access to housing.

By using an integrative services approach and a harm reduction model the Bridge Project strives to minimize the barriers to services that individuals with histories of substance use and mental illness often confront. In adherence to the harm reduction philosophy, the program encourages open, non-judgmental communication concerning substance use, and allows clients the opportunity to develop goals and strategies for reducing harm that may be associated with their use of substances. Consistent with this philosophy, service delivery is client

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driven as much as possible and treatment plans are developed with a respect for each client's readiness and self-identified needs.

Over the past three-and-a-half years, the project has learned a number of instructive lessons on how to work with multiply diagnosed clients, other providers and the owners and managers of hotels. A brief overview of the project as well as some of these lessons are highlighted here.

The Bridge Project Model of Care and Services

Location

The project is located in the Tenderloin district of San Francisco, home to a large population of indigent men and women. The Tenderloin is also the location of most of the city's single-resident occupancy (SRO) hotels. For a few of the homeless in the neighborhood, these hotels are often the only possible option they have for getting off the streets temporarily. Bridge Project clients are housed in these hotels.

Lutheran Social Services – The Bridge Project – Inter Agency Linkages

The Bridge Projects works as an interface between a multitude of medical services and housing services for homeless, multiply diagnosed clients with HIV/AIDS. Clients, while housing in one of the single resident occupancy hotels, have access to health services from a number of outside agencies.

Subcontracted Health Service Agencies

Designated persons from each agency make up the Bridge Project staff. Staff visit clients at their hotel residence.

AIDS Benefit Counseling Center
SSI/SDI Applications

Family Services Agency
Mental Health Services (Therapy Medication, SSI Evaluations)

Tenderloin AIDS Resource Center
Substance Abuse Counseling

Tom Waddell Health Center
Medical Care

Visiting Nurses Hospice
Nursing and Home Health Services

Single Resident Occupancy (SRO) Hotels

SROs are not service partners, but rather for-profit hotels in need of income. The relationship is mutually beneficial: hotel owners are assured of residents, clients are assured of a place to stay.

Hotel #1

Hotel #2

Hotel #3

Hotel #4

Services

The Bridge Project provides transitional housing and comprehensive integrated services for up to 18 months to individuals who are homeless, HIV-positive, chemically dependent and/or mentally ill. The project involves the collaboration of six service providers and agreements with five SRO hotels in the Tenderloin. The services are designed to offer chronically homeless individuals an opportunity to improve their health, well-being, and quality of life while addressing and resolving issues that have contributed to their housing instability. By combining stable shelter with comprehensive services provided on site, the program attempts to mitigate the stresses associated with chronic illness, addiction, isolation, and poverty.

Provider Team

Lutheran Social Services functions as the lead agency for the six-member collaboration group. Staff from the service agencies function as a multi-disciplinary team. The team members provide a range of services including: primary medical care, home nursing services, mental health services, substance use counseling, support groups, case management, benefits advocacy, acupuncture, massage, and health education. All services are voluntary and client-focused. This approach fosters trust and stronger connections between staff and client. Clients pay 30 percent of their income for rent, and are required to enroll in money management services at Lutheran Social Services to ensure the timely payment of their rent.

Lutheran Social Services – The Bridge Project Staffing Patterns

Bridge Projects staff is comprised of persons from a number of pre-existing agencies. Although connected to different agencies the staff works together as a group. Staff management is challenging due to the number of staff and differing personnel policies at each agency.

Agency – Hours – Staff Title

Lutheran Social Services - 3 Staff Persons
0.6 FTE – Program Manager – Clinical
1.0 FTE – Program Manager – Housing
1.0 FTE – Ad. Asst./Database Coordinator

AIDS Benefit Counseling – 1 Staff Person
0.5 FTE – Benefits Counselor

Family Services Agency – 6 Staff Persons
0.8 FTE – Social Worker #1
0.6 FTE – Social Worker #2
5 Hours/Week – Psychiatrist #1
5 Hours/Week – Psychiatrist #2
3 Hours/Week – Psychologist #1
3 Hours/Week – Psychologist #2

Tenderloin AIDS Resource Center – 1 Staff Person
1.0 FTE – Harm Reduction Counselor

Tom Waddell Health Center – 3 Staff Persons
0.5 FTE – Physician
0.5 FTE – Health Worker
2 Hours/Week – Nutritionist

Visiting Nurses Hospice – 1 Staff Person
1.0 FTE – Nurse

Total Bridge Project Staff: 15 Full and Part-Time

Lessons Learned

Lesson #1: Stable housing needs stable relationships.

Maintaining adequate housing for project clients is a fundamental challenge. The extremely low vacancy rate in San Francisco has significantly increased the cost of housing. Even poor quality housing is in high demand. Consequently, cultivating and sustaining good relationships with hotel owners is critical to the long-term stability of the housing resources available to clients.

Stability as a common objective

SRO hotels are private businesses and increased income is the only real incentive the owners have for working with a project. There is little opportunity to build collaborations between them and project staff or clients based on shared goals or philosophies. One potential shared objective is the stability of the clients. While hotel owners appreciate having stable tenants as it ensures a steady income, providers appreciate stability as it is an important marker of progress with a client. The Bridge Project staff exploit the benefits of stability when negotiating access to SRO housing.

Intervening in difficult situations

The project's staff includes a full-time program manager for housing who is responsible for identifying and

The Bridge Project has been very successful in stabilizing clients... 57% (42) retained their housing for more than six months.

securing additional housing. In addition, the program manager for housing ensures that the project maintains good relations with hotels owners and staff which often means intervening in conflicts between project clients and hotel staff. A number of hotel owners terminated their relationship with the Bridge Project because of difficulties they experienced with project clients. In order for the project coordinator to intervene and resolve potentially damaging situations as quickly as possible, she has provided hotel owners with contact information so that she can be reached 24 hours a day. The program manager for housing also makes an effort to interact with the owners on a daily basis thereby building good will for the project and remaining apprised of any developments at the hotel that may affect the project.

Security deposit

Having learned how a client's behavior can cost future access to a hotel, the project staff created a number of ways of buffering the impact of troublesome clients. The first was to set up a mechanism whereby new Bridge Project clients pay a $100 security deposit when they first move into a hotel. This money can be used to reimburse the hotel for any damages caused by the client. Since clients seldom have the money needed to pay the security deposit, the $100 is frequently loaned to them through the agency's money management program. They repay the money over several months once their entitlements have been secured.

Housing agreement

The second mechanism for minimizing the likelihood of clashes between project clients and hotel staff, was the creation of a housing agreement. Since none of the hotels use lease agreements with their tenants there is no explicit contract stating the terms of their residence in the hotel. The housing agreement performs a similar function to a lease in that it explicitly states what is expected of clients if they wish to remain housed. Project staff reinforce the rules of the hotel during their multiple visits with clients. Signing and abiding by the agreement is a lesson that clients are able to take with them when they transition into permanent housing.

Lesson #2: A strong team needs a strong foundation.

Building the team

Many of the Bridge Project staff are not employed by Lutheran Social Services, the lead agency for the project, but by one of the collaborating agencies. Thus, in addition to ensuring access to a range of client services, the linkages between the collaborating agencies has also ensured access to highly talented, trained and seasoned providers familiar with both the Tenderloin and the population served. As a result, the project was able to assemble a strong interdisciplinary team. Building a team in this way enhanced the strength of the collaboration beyond the conventional sharing of services.

Identification with the project

It is not apparent in day-to-day project activities that staff are employed by different agencies. There are a number of reasons for this. Firstly, all staff are located at Lutheran Social Services and, with few exceptions, work full-time on the project. Secondly, staff work closely with each other and have developed strong professional relationships built on common experiences and mutual respect. Thirdly, they share a strong commitment to the population and the principles by which the project operates. And finally, they have all contributed to the creation of the Bridge Project model. This has provided a strong sense of purpose. The result is that staff identify primarily as members of the project team and secondarily as employees of a particular agency.

Linkage between agencies has ensured access to talented, trained and seasoned providers familiar with the population served.

Personnel protocols

One of the problems with building a team from employees of six different agencies is the confusion that can occur with regards to supervisory authority, accountability and personnel procedures since each agency has different personnel policies and most of the program staff report to two supervisors from separate agencies. In order to minimize these confusions, it was necessary for the program directors from the collaborating agencies to develop protocols addressing issues such as hiring procedures, accountability and performance evaluations. These and other issues are dealt with through monthly meetings and an annual retreat involving program directors and project staff. At these retreats the organizational structure is reassessed, communication is strengthened both among agencies and between administrators and program staff, and the goals and priorities of the project are reviewed.

Lesson #3: Assist clients in relationship building.

The needs of multiply diagnosed clients are extensive and accessing services is inevitably difficult. The Bridge Project does not have all the necessary services in-house and must, therefore, link clients with other service providers. Many of the clients have had negative experiences in conventional health care environments and are wary of engaging with new providers. A critical part of the work the project staff does is assist clients to build trusting relationships with other providers. The Bridge Project staff are aware of the importance of ensuring that clients are linked with a primary health care provider with whom they can form a stable and trusting relationship that will last beyond the time the individual is a project client. Working with providers in partner agencies helps as they are familiar with the population. When working with non-partner providers, the staff play a critical role in coordinating client appointments, following-up with clients to assist them in getting to their appointments, and helping to resolve any difficulties that may arise.

> Mental health services are the most difficult services for Bridge Project clients to access both while they are in and after they have transitioned out of the program.

Lesson #4: Unconventional methods — the key to mental health services.

Mental health services have proven the most difficult for Bridge Project clients to access. The availability of in-house treatment has been crucial. Repeated efforts to access services through the mental health system have demonstrated the numerous barriers confronting this population. Few mental health services complement the harm reduction approach that characterizes the Bridge Project. In addition, most mental health providers are not experienced in working with a population in which traumatic experiences are as pervasive as they are among these clients. With the assistance of a psychiatrist and psychologist and through a network of peer contacts, the Bridge Project staff have developed unconventional methods of providing mental health care. This has involved integrating mental health interventions into many of the other elements of the project, such as consultations with the nursing staff, participation in activities groups (such as the cooking group) and in the day-to-day interactions with the staff as they make their rounds of the hotels.

Project Bridge Chronology

This chronology of implementation and development demonstrates the steps and length of time involved in developing program components. The chronology also presents the barriers project staff encountered and the process involved in overcoming them.

November 1996

- Lutheran Social Services receives notification of HOPWA award to fund the Bridge Project, an intervention for multiply diagnosed and HIV-positive homeless men and women.

January 1997

- Bridge Project manager is hired.
- Scarce and expensive housing resources are identified as an immediate barrier. Since writing the proposal, vacancy rates in San Francisco dropped to less than 1 percent, rents escalated, and the number of SRO units in the Tenderloin diminished due to gentrification.

March 1997

- The Bridge Project interagency collaboration is established by the signing of subcontracts with six collaborating agencies. A partnership committee consisting of representatives from all partner agencies is formed. The collaborators hire the following staff: service coordinator, benefits counselor, registered nurse, substance abuse counselor/outreach worker, social worker, health worker and nurse practitioner. First staff meeting is held on March 31.
- One potential SRO is identified.

April 1997

- To build the Bridge Project team, staff concentrate on operating procedures, communication processes, roles and responsibilities, coordinating services, creating client forms and charts, and program philosophy. An administrative assistant is hired.
- Agreements are signed with the three SRO hotels. Improvements have to be made to the rooms at one hotel before clients can be housed.
- Staff offices for client meetings are set up at two of the hotels.
- The first clients are enrolled in the program.

May 1997

- A focus group is held with case managers from various social service agencies in the Tenderloin to elicit suggestions for how to develop the interagency referral process.

June 1997

- 34 active clients

July 1997

- A conflict develops between SRO managers and clients. Managers insist that problem clients be moved out; clients complain hotel staff are disrespectful. Despite poor conditions at one facility, clients evicted from other hotels are sent there in order to keep them housed.

August 1997

- 43 active clients

September 1997

- A one-day retreat is held with program staff to focus on team-building and communication.
- One of the original group of hotels refuses to accept more clients because of disturbances caused by some residents. The project now relies on two hotels to accommodate clients.
- One of the partner agencies arranges for a psychiatrist to be on-site at the hotels.

October 1997

- An additional psychologist is added by partner agencies to provide on-site therapy and SSI evaluations.
- 41 active clients

November 1997

- An agreement is signed with an additional hotel while two others verbally agree to house clients.

January 1998

- **A total of 73 clients served to date; 44 active clients.**

February 1998

- An additional team social worker is provided by a partner agency.

March 1998

- A home health worker joins the team.

April 1998

- A partner agency provides clients with access to a nutritionist. A second staff retreat is held.

May 1998

- Two of the original hotels refuse to accept new clients.
- **46 active clients.**

June 1998

- One of the hotels with which there is a verbal agreement is no longer a viable site for the project.
- 50 active clients.

July 1998

- A program manager for housing is hired to work solely on developing and managing relationships with the SRO hotels.
- Rents at the primary facility increase from $365 to $400 per month.

August 1998

- An agreement is signed with a new hotel. Two hotels now accept clients.

September 1998

- A third retreat is held with staff and administrators.

October 1998

- An agreement is signed with a new hotel. Three hotels now accept clients.

December 1998

- In response to tension between the staff and partnership agencies, personnel guidelines addressing issues associated with dual reporting of staff are drafted and reviewed by the partnership committee.

January 1999

- The relationship with one of the hotels is terminated due to inflated rents and safety concerns. Clients are transferred to the remaining two hotels.

February 1999

- To reduce incidents that threaten project relations with the SRO hotels, the program manager for housing develops a rental agreement to be signed by all clients when they start receiving rental assistance. The agreement outlines a minimal code of conduct.
- A fire at one hotel causes extensive water and smoke damage requiring evacuation of residents. More rooms are available at the other hotel, but concerns about safety and poor conditions make it the site of last resort.

April 1999

- 132 clients served to date; 59 active clients.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the Bridge Project, you are welcome to contact the project directly and request technical assistance. You may contact either of the following:

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The Diamond Project, Health Care for the Homeless, Inc.

Linking Multiply Diagnosed Homeless Persons to Care

Authors: Laura Gillis, Tony Tommasello and Robert Sember

The lessons presented come from the first four years of the project's five year grant cycle. Outcomes evaluation findings will be available following the completion of the project's final year.

Introduction

Getting adequate medical and supportive services to homeless, HIV-positive men and women who are also dealing with mental health difficulties and substance abuse is one of the most difficult challenges in the AIDS epidemic. Health Care for the Homeless, Inc. (HCH) in Baltimore has spent years providing care to homeless men and women and has developed highly effective methods to engage and retain these individuals in primary health care. With the Diamond Project, the agency formally took on the challenge of deepening these skills in order to work with multiply diagnosed persons living with HIV/AIDS.

By combining aggressive outreach technology with comprehensive integrated medical service delivery, Diamond Project staff engage with multiply diagnosed individuals on the street and bring them into treatment. Both the outreach and service delivery components of the project are based on an innovative client-centered approach derived from both harm reduction principles and stages of change theory.

Over the past four years project staff have experienced the strengths and limitations of this approach first hand, enabling them to refine the original intervention model.

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The Diamond Project Model of Care and Services

Location

The Diamond Project is housed in the Health Care for the Homeless organization in Baltimore, Maryland where it is estimated that there are approximately 1,800 individuals who are homeless, HIV positive, mentally ill and/or substance abusers. The mission of HCH is to provide health related services, education and advocacy to reduce the incidence and burdens of homelessness. The agency works to remove health related obstacles that prevent persons from resolving their homelessness.

HCH is the sole provider of comprehensive medical, mental health, addictions, and social work services to homeless persons in Baltimore. In 1995 the 54-member staff of health care providers and support personnel in HCH centers throughout the state experienced 42,657 encounters with 8,764 different individuals.

Services

The Diamond Project's target population is HIV-positive homeless individuals with drug abuse, mental illness, and/or alcohol abuse co-morbidity. The goal of the project is to engage members of the population on the streets, establish a relationship with them, facilitate their entry into primary care, and assist them in securing housing. The project employs four strategies to accomplish this goal: outreach, integrated multidisciplinary service delivery, community resource linkages and access to housing resources.

Diamond Project outreach workers operate in multidisciplinary teams at several sites where homeless people congregate. Each team includes a registered nurse, a peer leader (indigenous worker), and an addictions counselor. The team concentrates its street outreach in the Upton Station area of Baltimore that has active drug traffic and a high concentration of addicts living in an eight-block area. Outreach is also conducted at four shelters, the Baltimore City Needle Exchange van and at two soup kitchens.

The goal of the outreach effort is to motivate homeless individuals to access comprehensive primary care and a range of social services. Service provision begins during outreach, however. The Diamond teams provide nursing assessments, resource information, and HIV prevention education and addiction resource information to individuals encountered on the streets. When a client accepts a referral to HCH and enters the clinic, a full range of integrated services is brought to bear on his or her medical, social, and mental health problems. Clients can receive these diverse services within the same building.

Through a close partnership with City of Baltimore Department of Housing and Community Development's Hope Project, clients are able to access the Community Resource Center run by the Health Education Resource Organization (HERO). The Resource Center provides a drop-in center with structured activities, vocational training and amenities. The Hope Project also operates beds in transitional housing for the medically fragile clients and supports transition to housing.

The Diamond Project outreach teams engage and transition homeless individuals into care

Lessons Learned

Lesson #1: Homeless individuals with multiple needs do seek care.

By using a client-centered approach, the Diamond Project outreach teams and the providers at Health Care for the Homeless have been able to identify, engage and transition multiply diagnosed men and women into care. The success is based on an increasing appreciation for a client's readiness to engage in care and strategies to strengthen their motivation through a harm reduction model of care, as well as efforts to make care readily accessible.

Clients served

Since the implementation of outreach services in March 1997, the two Diamond teams have encountered 3,769 clients on outreach. Of these, 3,059 (81 percent) were new clients to HCH. More than a third of those encountered in outreach, 1,333 (35 percent), came into the clinic for services. While understandably much smaller, the number of HIV-positive clients encountered during outreach and transitioned into care is significant. Through the outreach efforts, 112 HIV-positive individuals have been recruited into the project. Of these, 36 percent are AIDS defined, 39 percent are HIV-positive with a persistent mental illness and substance abuse, and 38 percent also have other major illnesses, such as diabetes and cancer.

Stages of change

The program draws heavily from the Transtheoretical Model 1 of Prochaska and DiClemente to improve client success. This model is concerned with the difficult process of behavioral change, which it breaks down into five stages: pre-contemplation, contemplation, preparation, action, and maintenance. The model predicts that poorly motivated individuals have a low probability of seeing an intervention through to completion, thus producing inefficiencies in the delivery of care to them. Providers need to tailor their interventions so that they are appropriate for these various stages and can assist individuals move toward the action and maintenance phases of change.

The Diamond Project team believes that without proper motivation before engaging health care services, homeless individuals are unlikely to succeed. Once they have engaged in care with the clinic staff, they need continued support and assistance to improve treatment participation and response. The stages of change model helps both the outreach teams and service provider staff determine a client's level of motivation so that they can intervene appropriately.

Strengthening motivation

Outreach staff, hoping to entice individuals into care, try to determine an individual's level of motivation. Once motivation has been determined, staff will work with the client in a manner that is encouraging but not threatening. For example, outreach workers who engage a person in the pre-contemplation stage simply engage that individual in conversation. After a number of encounters, when a foundation of familiarity and trust has been established, team members share information about treatment and reassess the individual's level of motivation.

Contrary to the image of this population as treatment resistant, individuals are aware and are often willing to engage care. A client's readiness for treatment is assessed at a number of points. Along with needs assessment information, staff observe and note any behaviors indicating that a client is ready. Many clients are aware that they need services. For example 60 percent of Diamond project clients reported a need for mental health services; sixty-five percent of the clients reported a need for substance abuse services. Unfortunately, a client's motivation for treatment is inconsistent over time, therefore, program staff need to be attentive, providing support and encouragement.

Maintaining in care

The stages-of-change approach also has application for providers of in-house services who wish to retain individuals in treatment longer than what is usually expected. If a client, brought in through outreach, has reached the action stage, the interdisciplinary service team provides reinforcement to mitigate behavior that would normally result in the client dropping out of care.

The agency as a whole is oriented to providing access to care and support to those who engage with services. This is most apparent in the recognition that the life conditions of homeless individuals make it difficult to follow the conventions of traditional health care settings. Scheduling care for clients is only partially successful—clients do not show up for 50 percent of scheduled appointments, As a result, almost all services at HCH are available on a walk-in basis and there is a medical care team on call 24 hours a day. Rather than taking the approach that homeless individuals seeking care must fit in to the provider's schedule, the agency works to fit into the schedule of the client.

Lesson #2: Managed care is a barrier to care for indigent clients.

The Diamond outreach teams engage clients with the hope that the relationship between provider and client will be a bridge to care. With the advent of the 1115 waiver in the State of Maryland in July 1997, people receiving medical assistance are mandated into managed care plans. This is proving disruptive to the process of building a trusting relationship between provider and client.

Choosing a provider

Under the procedures used to transition or enroll individuals in managed care organizations, clients are sometimes pre-enrolled with a provider. This decision is made without their knowledge. HCH staff try to link them to their primary care provider of choice but this process takes an inordinate amount of time and while it is in process the agency is obliged to direct the client to the provider that has been selected for him or her. HCH is not reimbursed for providing care to clients who have been assigned to another provider. This is not only a problem when trying to assist specific clients, but is compromising the reputation of the agency as a place where care is readily accessible. Clients share information about their care with others in the homeless population resulting in the perception that some people will get turned away when they come to HCH.

System problems

Clients at HCH have reported a number of problems with the managed care system. One of the most common is the difficulty they have accessing the managed care organization for information or to change their enrollment. Clients have been placed on hold for an hour. Accessing a telephone is generally difficult for homeless people, it is seldom that they are able to do this for any significant length of time.

> ...people... are mandated into managed care plans. This is disruptive to the process of building a trusting relationship between provider and client.

Use of health advocate

In order to mitigate the barriers posed by managed care, HCH has developed programmatic and community responses. To help resolve problems encountered at the client and agency level, HCH hired a health advocate who educates clients about the Medicaid managed care program in Maryland, assists providers in resolving problems associated with switching clients to different managed care organizations and educates HCH staff about the requirements of different managed care organizations.

National managed care standards

To push for system change, HCH has joined a coalition led by the health officer of the Baltimore City Health Department to pursue universal health care in the state. The agency also collaborated in the creation of national managed care organization standards of care for the provision of services to homeless persons. These standards were submitted to Health Care Finance Administration (HCFA). Booklets on homelessness and managed care are now distributed by HCFA to all state medical directors.

Lesson #3: Building and developing a team takes time and skill.

Over the four years that the project has been in operation there have been many staffing changes within the Diamond Project and the agency as a whole. These changes have been made in order to streamline the functioning of the agency and to improve the efficacy and stability of

Diamond Project teams. It is clear that changes in the agency's organizational structure effects program level activities—this impact needs to be anticipated and directed in a way that is positive and minimally disruptive. The Project has also learned that a multidisciplinary team approach to outreach has strengths and vulnerabilities. With careful hiring decisions and supervision, a strong and stable team can develop.

...it has been important to ensure that the team does not become hierarchical...

Organizational changes

HCH has gone through a number of substantial organizational changes over the life of the project, including appointing a new executive director. The organizational structure of the agency has also changed, creating new administrative roles and responsibilities. While these changes have been positive for the agency, they have entailed a significant period of transition, which has affected the agency as a whole. For example, by creating new positions and eliminating others, the personnel has shifted. Some Diamond Project staff, seeing new opportunities in the agency, have left their positions and new staff have been brought in. This has required retraining and a slow down in activities as the project team reconstitutes itself.

In some cases, these changes have not affected the Diamond Project team directly. Instead, they have changed the roles and responsibilities of key individuals in the agency which has, in turn, changed supervisory structures. Such shifts can be reinvigorating as they bring in new ideas, but they can also be disorienting. By learning from the first series of changes, the project has been able to anticipate the effect of staffing changes and has developed procedures to minimize the disruption. These include ensuring that the skills of more experienced workers are shared with those who are less experienced.

Building a team

At the project level these changes have focused attention on the issues involved in establishing and maintaining an interdisciplinary outreach team. The teams are composed of a registered nurse, an addiction counselor and peer leader. By bringing together these diverse skills, multiply diagnosed clients can be provided with an immediate, high level intervention which quickly builds confidence in the provider and strengthens the motivation to enter into care.

Diverse skills

The peer leader is able to make an immediate connection with individuals because he or she is familiar with the day-to-day issues and needs of homeless individuals. Since close to 80 percent of the target population reports active drug use, the addiction counselor plays an important role from the very beginning in helping to prepare clients to enter treatment. The nurse is able to conduct initial health assessments of clients and discuss health issues with them in an informed and reassuring manner. Perhaps most important, however, individuals become acquainted during outreach with providers who represent the range of services offered at HCH. The team members are able to speak knowledgably about services and also communicate a sense of the culture of treatment in place at the agency. When the individual first visits HCH, members of the outreach team are also often there to minimize the anxiety associated with new places.

Using differences constructively

The range of professional skills and personal qualities they represented in the teams is both their strength and weakness. Structurally, the greatest tension exists between the nurse and the peer leader. The nurses are institutionally sophisticated and know how to develop and maintain organization systems. The peer leaders, on the other hand, are recent graduates of social service programs and know what it is like to be a client. The peer leaders have been homeless for significant lengths of time and their skills lie in their firsthand knowledge of the communities from which the clients come and the kinds of lives they lead as homeless persons.

While it has been important to ensure that the team does not become hierarchical, such as having the nurse and peer leader duplicate the provider-client relationship, it has also been important to acknowledge the different and complementary skills of team members. Teams need time to overcome assumptions about each members skills and to allow roles and responsibilities to develop. It is important for supervisors to facilitate and guide this process.

Risks of outreach

Outreach work is stressful and workers are at risk for secondary trauma. This is particularly the case for the peer leaders. After a number of difficulties resulting from effects of stress on the peer leaders, greater attention has been paid in team meetings and supervisory sessions to the well-being of the project staff. One of the best resources available to help protect team members is the bond they develop over time. The stress associated with working in the field combines with the shared experiences on the streets to form strong personal relationships between team members. These affections can also be a source of conflict and the team needs time to reflect on how it is functioning. In building a team it is important to determine not only whether the skills team members bring to their work are complementary but whether the individuals' personalities are compatible.

Diamond Project Chronology

September 1996

- Notice of grant award.

October 1996

- The HIV Multiple Diagnosis Initiative is named the Diamond Project. The initiative has four facets: homeless, HIV positive, substance abuse and/or mental illness.
- Recruitment of two addiction counselors and two peer leaders begins.
- Two registered nurses begin work.
- Contract between HCH and the evaluator developed.

December 1996

- Two addiction counselors and two peer leaders begin orientation as new staff members of the Diamond outreach team.

January 1997

- A registered nurse begins orientation at HCH as new staff member.
- Meeting with the director of the Baltimore City HOPWA program, to discuss evaluating the HIV Multiple Diagnoses Initiative across the continuum of care. Since the Baltimore City HOPWA program also received funding under the HIV Multiple Diagnoses Initiative through HUD, a HCH registered nurse and an addiction counselor will provide services at the proposed Maryland Resource Center operated by the Health Education Resource Organization (HERO)

March 1997

- Diamond team starts outreach to soup kitchens, shelters, the Baltimore City Health Department Needle Exchange Van and streets for 32 hours per week.

April 1997

- Second registered nurse begins.

May 1997

- Mental health coordinator leaves.
- Project director assumes responsibilities for coordinating the team which consists of one therapist and one 20-hour-per-week psychiatrist.

June 1997

- New HCH nursing services coordinator hired to co-lead the medical team and supervise Diamond nurses.

July 1997

- Addiction coordinator resigns.
- The addiction team, which includes the two Diamond addiction counselors and two peer leaders, is restructured to include an addiction operations manager.
- HCH expands existing contract with University of Maryland Department of Community Psychiatry to include all mental health services at HCH.
- HCH converts to a new database.
- Implementation of the 1115 waiver.
- Mental health services are segregated to an organization that controls access to the public mental health system.
- Evaluation team and project director meet with the medical director and pertinent staff with other service providers to discuss identification of homeless HIV-positive patients within their clientele to interview as part of the control cohort.

August 1997

- 542 clients have been engaged in the outreach setting by the Diamond Team and 201 have come into HCH for services. 14 clients are HIV positive and meet the criteria for inclusion into the Diamond Project cohort.
- Evaluation team and project director meet with the medical director and pertinent staff at an outpatient clinic of the University of Maryland Medical System that serves HIV-positive individuals to discuss identification of homeless HIV-positive patients within their clientele to interview as part of the control cohort.

October 1997

- New addiction coordinator and a new addiction operations manager are hired. They provide direction and supervision to the two Diamond Project addiction counselors and two peer leaders on the team.
- Quality management director resigns. A replacement is hired.
- The Diamond Project protocol gains full approval by the Institutional Review Board of the University of Maryland at Baltimore.

November 1997

- HCH President/CEO informs staff that she will leave agency by February 1998

December 1997

- Director of community relations is named acting president/CEO. Search for new president/CEO initiated.
- Request permission from HRSA to hire a staff member to conduct client interviews. The original project plan designated the utilization reviewer for that task, however, tracking more than 1,200 clients engaged in the outreach is a full time job.

January 1998

- Diamond nurse resigns and is replaced by an internal candidate.
- New contract implemented for mental health services with the community psychiatry program at University of Maryland.
- Psychiatric clinical nurse is transferred from University of Maryland to HCH and becomes the mental health team coordinator.

February 1998

- Statistical data assistant hired.
- The core data elements for the cross-site evaluation tool along with the local evaluation tools are integrated

into the general assessment tool (GAT).

- The GAT will be used for the Diamond cohort clients and the clients at the control sites for initial assessments and the six-month and twelve-month follow-up.

March 1998

- Two HCH staff members, an addiction counselor and a nurse, start providing 16 hours of addiction and nursing services to clients at HERO as part of the HOPE (HOPWA) project.

April 1998

- Diamond interviewer hired.
- An HCH peer leader becomes the team peer leader.

May 1998

- Addiction counselor resigns.
- The acting president/CEO becomes the HCH president/CEO.
- Agency restructured. Diamond project director is promoted to clinical operations officer.

June 1998

- Local evaluation modified from four control sites to two.

July 1998

- Diamond nurse moves to a new position in the agency.
- Two Diamond peer leaders apply for the addiction counselor position. One is hired and the other resigns.
- 1944 homeless persons have been encountered by outreach setting since March 1997; 42 clients are confirmed HIV positive with a diagnosis of substance abuse and/or persistent mental illness.

September 1998

- Addiction counselor is promoted to peer leader supervisor.
- Recruitment started for an addiction counselor.
- Program evaluator and project director present initial data at multi-site evaluation meeting.

October 1998

- Two new peer leaders start.

November 1998

- Addiction counselor and new nurse begins.

December 1998

- Peer leader leaves.
- Provider survey conducted in control sites and at HCH.

January 1999

- Nursing services diverted to Project PLASE, a transitional shelter and member of the HOPE project.
- Addiction services increased from 16 to 18 hours at the Maryland Resource Center.
- Statistical data assistant resigns.

February 1999

- Diamond Project teams have engaged 2,589 clients in outreach and 62 percent are new clients to HCH. There are 63 clients in the Diamond cohort.

- Provider staff from the medial, mental health, addictions and social service teams are inserviced on the use of Orasure.

March 1999

- HCH becomes designated counseling and testing sites (CTS).
- New statistical data assistant hired.

April 1999

- Evaluator and project director present the poster, *Broken promises: Managed care as a Barrier to Outreach Services* at the National Health Care for the Homeless Conference, Washington, D.C.

May 1999

- New peer leader begins.
- Addiction coordinator becomes HCH program development coordinator.
- The addiction team is restructured. The peer leader supervisor and the addictions operations manager positions are eliminated; two coordinator positions created—addiction outreach coordinator and addictions treatment coordinator.
- Addictions outreach coordinator hired and the addiction counselors and peer leaders report to her directly.
- Addiction treatment coordinator hired.

June 1999

- A new position, clinic nurse manager, is created in the medical team.
- Nurse resigns and recruitment for two nurses is initiated.
- Project director presents *Improving HIV care and prevention into the 21$_{st}$ century: Integrated care for multiply diagnosed* at the Veterans Affairs conference in Washington, D.C.

July 1999

- Diamond Project teams have engaged 3,166 clients in outreach and 70 percent are new to HCH; 30 percent of the 3,166 clients have come into HCH for services; 77 clients are in the Diamond cohort.

November 1999

- Project director, addiction outreach coordinator, and an addiction counselor present the Diamond Project model at the U.S. Conference on AIDS in Denver, CO.

December 1999

- HCH management team is restructured.

January 2000

- Evaluator and project director present the Diamond Project at a community-based research forum at Johns Hopkins University School of Public Health to students and faculty.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Diamond Project, please contact

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Hope Harbor/Harvest Hills, Salvation Army

Long Term Housing and Supportive Services to Individuals and Their Families

Authors: Jennifer Wurm, Louise Simons and Jo L. Sotheran

Introduction

The Salvation Army has served homeless people in the downtown Minneapolis area for more than 50 years at the Harbor Light Center. The center provides emergency and transitional housing facilities and is the largest provider of homeless services in the city and surrounding county. Ancillary services including transportation, medical care, detoxification and case management also are provided at the center. Drawing on both internal resources and external linkages, the Harbor Light Center has evolved into a comprehensive service center for the needs of homeless people, whether housed at the center itself or elsewhere.

In recent years the Harbor Light Center has experienced a whole new challenge. Minneapolis has one of the largest populations of HIV-infected people in the Midwest, this is reflected in the Harbor Light Center client demographics—an estimated 20 percent of the center's clients are HIV positive. A statewide needs assessment carried out in 1995 identified housing as a critical need for people with HIV/AIDS. This need was found to be particularly acute in the Minneapolis area, which has experienced a booming economy, real estate development and increasing rents. This economic growth, combined with an almost nonexistent vacancy rate, has rendered affordable housing unavailable to those who are considered less than completely desirable tenants, including those with unstable residential histories, substance use or mental health problems or the stigma of known HIV.

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The design incorporates flexible leasing arrangements to allow for needed absences,,, enabling residents to live out the entire disease course in a stable environment.

The design of the project aims to increase longevity and improve health outcomes of the multiply diagnosed HIV-infected residents by providing clients the means to overcome practical barriers to treatment and services, extending the reach of existing services to include permanent housing, and empowering residents to make better use of services and achieve greater psychosocial stability.

This report chronicles a number of instructive lessons learned by the project in the development and construction of single room occupancy units for multiply diagnosed individuals and their families. A brief timeline of activities is also included.

The Hope Harbor Model of Care and Services

Location

The Minneapolis-St. Paul area is best known for its frigid winters, ice festivals, well-kept cities, stable economy, educated citizenry and a generally high quality of life. However, the area also has a substantial population of homeless and destitute people, both from the immediate area and drawn from elsewhere by Minneapolis' role as a regional economic and cultural center.

Services

The project was originally envisioned as a supportive housing facility that would house both families with HIV/AIDS and homeless single adults, in a newly constructed building in close proximity to the existing Harbor Light Center, located in downtown Minneapolis. Although the Harbor Light Center provides emergency and transitional housing facility, there is little permanent housing available for the type of population served by the center. The Hope Harbor was designed to provide critically needed permanent long-term housing for this population.

Designed explicitly as supportive housing, the project is based on the Hope principle: Housing Opportunities for People to Excel. In contrast to other area facilities, Hope Harbor project is designed to assist the hardest-to-serve homeless population—those with prior histories of serious residential instability, mental illness, and/or substance abuse. The projected 100 single residence occupancy (SRO) units will provide a stable and supportive housing environment and assist clients in the effective use of services offered by the Harbor Light Center.

As part of this overall development, the Hope Harbor project plans to include 12 HOPWA-funded single units, set aside for members of the target populations who are also infected with HIV/AIDS, as well as several other units for HIV-infected families. This project is designed with a number of distinctive features appropriate to residents with and without HIV.

Although a percentage of units will be funded with specifically HIV-related HOPWA funding, neither they nor their tenants will be visibly differentiated from other residents. The provision of individualized packages of services through the Harbor Light Center will maintain the privacy of tenants. Hope Harbor is to become permanent, individual housing for people with multiple problems.

The housing project design incorporates flexible leasing arrangements to allow for needed absences for medical and other treatments, enabling residents to live out the entire disease course in a stable environment. Deliberate attempts were made to create or enhance a sense of community for residents, to contribute to social support and empowerment. The location and facilities will enable residents to maintain or re-establish contact with family and friends in their nearby neighborhoods of origin. Potential tenants will have input into aspects of building design and a tenants' organization will continue to be involved in the project. Finally, individual and private living spaces will be complemented by public spaces for informal social activity and planned activities for residents.

Lessons Learned

Lesson #1: Limit the number of new elements within the project.

Hope Harbor and Harvest Hills are both almost completely new initiatives. Although embedded in an agency with substantial resources and experience, these projects involved a new and innovative program model (centralized low-threshold housing combined with off-site individualize services), totally new construction (and in one case on a newly-acquired site), and funding usage new to the agency. Any one of these elements would have been challenging. The combination used up enormous amounts of staff time in learning and negotiating new areas. Additionally, unforeseen delays in internal and external operations complicated the project timeline— negatively affecting funding possibilities, increasing costs and altering the design of the project. The project was originally designed to be a single facility, but after review, administrators at the parent agency decided that the project be split into two facilities—one that would house families (Harvest Hills) and one that would serve individuals (Hope Harbor). Groundbreaking for both projects is now scheduled for early 2001—two years behind schedule.

> One indirect cost is the time spent coordinating different funding sources' requirements and timelines.

Lesson #2: Understand the advantages and disadvantages inherent in utilizing multiple funding sources.

It is unlikely that funding sufficient for a large scale project can be acquired from a single source. The projected 12 units of HOPWA-funded housing are embedded in a larger overall project. While a larger project allows long-term savings (especially in areas such as construction) from economies of scale, it also creates additional complexities. Multiple funding sources might be necessary. One indirect cost is the time spent coordinating different funding sources' requirements and timelines. The Salvation Army also utilized an unfamiliar funding source, MHFA tax credits, and delays were attributable both to the staff's learning curve and to learning the way the tax credit system works in practice.

Lesson #3: Consider agency hierarchy and policies when planning project timelines.

The Hope Harbor and Harvest Hills projects are evolved within two overlapping environments: the local civic environment and the agency environment within which the project team is embedded. Being part of a larger organization, in this case the Salvation Army, gives the project team a wealth of resources and experience to draw on. However, the Army's hierarchical organization means that team decisions are subject to review and revision at higher organizational levels, which are often unfamiliar with the local area and are less concerned with completing the project than with ensuring adherence to overall Army procedures designed to safeguard the organization as a whole. A number of aspects, including the decision to relocate the family housing out of Minneapolis proper and the financing arrangements and construction contracting, were changed after consultation with territorial and regional offices, resulting in delays. Other obstacles have arisen in the civic environment with local planning and zoning commissions. In both cases, some of these delays could have been avoided by starting the educational and exploratory processes earlier in the project timeline.

The Hope Harbor/Harvest Hills Chronology

October 1997

- A project team of Salvation Army staff begins developing a supportive housing project for homeless families and individuals in the downtown Minneapolis area. A series of meetings focused on funding, construction costs, soil correction and public support begins.

November 1997

- Potential funding sources identified. Proposals for site survey, soil boring and environmental analyses are submitted to territorial headquarters for final approval.

December 1997

- Project team continues to study potential funding opportunities and reviews the project design, including floor plan, room size and day care area.
- Review of criteria for contractors.
- Selection of a contractor for presentation to the Salvation Army's divisional and territorial headquarters for final approval.

January 1998

- Project team identifies the low income tax credit program as a possible funding source. Team investigates this option, as this would be the Army's first time using this type of funding.
- The project team sets up a series of meetings to establish a working relationship with the MHFA.
- The project team presents the project to the Harbor Light Center Advisory Board, which, in light of the urgent need, argues strongly for an expansion of two or three times the number of proposed SRO units.

February 1998

- An attorney is retained specifically for tax credit issues.
- An application for tax credits is submitted. If approved, it will fund approximately 90 percent of the newly enlarged project, supplementing the HOPWA funding which covers development of units set aside for HIV-infected tenants.
- Lack of final approval from territorial headquarters delays preliminary cost estimate.

March 1998

- Territorial headquarters expresses concern about the bidding process used to select the contractor.
- Discussion continues on the low income tax credits, the project team anticipates that funding will be in place by Fall 1998 and that construction will start shortly after. Once the project is approved, funding must be utilized within three years.
- Discussions for the design/process bid for mechanical and electrical systems: a mechanical engineer will identify and describe the proposed mechanical systems so that mechanical contractors can bid on comparable tasks.
- Approval is received for survey and environmental testing.
- Legal staff and project team discuss the participation of the Salvation Army in the limited partnership agreement that underlies the project.
- An initial estimate from the proposed contractor is in the range of previous estimates for the project.
- The Minneapolis Zoning Department revises its interpretation to require rezoning rather than simply a conditional use permit as had originally been discussed.

April 1998

- The project's attorney recommends review of several legal options about the zoning.
- The Salvation Army's territorial headquarters staff expresses concerns about a variety of issues, including

funding, liability, loan structure and public relations. Additional approvals for the partnership agreement and tax credit funding will be delayed until the committee can come to resolution.

May 1998

- In light of delays in the approvals process, much of the funding from multiple sources that had been earmarked for the project is now unavailable.
- Staff decides to initially develop the 12 HOPWA-funded units while pursuing other funding for the remainder of the proposed project.

June 1998

- Territorial headquarters announces all issues have been resolved, but that the project should be pursued as two separate facilities. The homeless family campus should be separated from the housing for homeless individuals, so as to provide a more stable and safe environment for the families and children.
- The family housing for persons with HIV/AIDS (Harvest Hills) will be moved off of the Hope Harbor site.
- A subcommittee is formed to seek another site. Hope Harbor will become a program for low income, individual, single room occupancy housing.
- The exact configuration and number of units for Hope Harbor is undetermined, but estimated at 96 units. As a result, site design will have to be reevaluated.

July 1998

- The project team continues to work on project design and approval.
- Anticipated tax credit financing will be required as part of project funding.
- The building program is revised to include 92 units of low-income, SRO-style housing as well as storage and public-use spaces.
- The Salvation Army immediately begins searching for an alternative site for Harvest Hills.
- A site in Mounds View area is located and a purchase agreement is drafted.
- The architect presents several drafts of the design adapted for the Mounds View site. The size of the site suggests a multistory design, which dictates revision of initial cost estimates.

August 1998

- Project design and planning continue. Public-use (chapel, gymnasium) spaces will be included but built using separate funding.
- The Salvation Army forwards the draft purchase agreement for the Harvest Hills site to territorial headquarters for approval.
- The MHFA requires the Salvation Army to have site control as soon as possible; following this, the site must be surveyed to permit soil borings to proceed.
- Tentative date for groundbreaking is now Spring 1999.

September 1998

- The land in Mounds View, owned by the city, is approved by the development board and is scheduled for review by the city council in late October.

October 1998

- Several different plans are reviewed by the project team, the one selected foresees the development of 96 units of SRO housing with a main floor including social services offices.
- New architectural plans and drawings are needed due to the change in the program's design and size.
- Land purchase negotiations continue.

- An additional barrier to public funding is presented by the relatively high cost per unit dictated by the inclusion of space for child care and social service facilities that are a distinctive feature of this development, as well as the lack of definitive site control.

November 1998

- The purchase of land in Mounds View falls through.
- An available site in Coon Rapids includes an existing church.
- The Salvation Army signs a purchase agreement for the property and waits for final approval from the (seller's) church council members. This site would have the day care and administration space available.

December 1998

- The Salvation Army begins the necessary steps for zoning approval at Coon Rapids site.
- Preparing for the new round of funding applications in early 1999, the team seeks to solidify the cost estimates for the project.
- Securing cost estimates requires an official authorization for the architects to develop preliminary plans, approval of the selected contractor, a site survey for the architect to use in placing buildings, agreement on program and selection of preliminary plan for the architect to develop. All of this is needed so that the contractor can accurately estimate costs and timeline revision.

January 1999

- A petition for the necessary rezoning is submitted to the City of Coon Rapids.

February 1999

- Work starts on needed steps to secure tax credits.
- The Harvest Hills rezoning request is denied by the City of Coon Rapids.

March 1999

- As it becomes clear that rezoning is needed to build the Hope Harbor project, the team starts working with the City of Minneapolis on the application for rezoning.

April 1999

- The Hope Harbor zoning application is delayed. The city has placed a moratorium on any rezoning until the new zoning code currently being drafted, is approved and in force.
- The Harvest Hills development team considers a revised design (made up of four duplexes) for the site that would not require rezoning.
- The revised concept is submitted to the City of Coon Rapids for a preliminary conditional use permit approval, which is granted.

October 1999

- Review and planning tasks continue with both projects.

November 1999

- The revised city zoning code is approved and the Hope Harbor rezoning application process is restarted.

December 1999

- Meetings are held to discuss the ways to reduce the cost of the Harvest Hills project and keep it in line with funding source guidelines.

March 2000

- The Salvation Army hires a property coordinator and program director for both Harvest Hills and Hope Harbor.

- The revised preliminary construction cost estimate for Hope Harbor is estimated at around $6.25 million, instead of the previous estimate of $4.75 million. Construction costs have risen at least 11 percent in the past year.
- Meetings held to discuss cost reduction for the Hope harbor project.
- Construction estimates for Harvest Hills are now $1,226,947 having increased since September 1999 from $1,163,043.
- Project team begins discussion of cost saving measures, using typical current costs per square foot for apartment buildings as a point of comparison.
- The team decides to eliminate the play area as well as nearby sidewalks to reduce costs, along with other minor cost-cutting revisions.

May 2000

- Final construction documents are completed for Harvest Hills.
- The Coon Rapids city planner informs project team that the property must be replatted to reflect the new design and that the project will be subject to a public hearing process in Coon Rapids.

June 2000

- The Salvation Army presents the Hope Harbor project to the Minneapolis planning commission.
- The commission tables the project for one month to give the neighborhood time to review the facility.

July 2000

- The project team holds meetings with neighborhood businesses and law enforcement.
- The police department requests changes in landscaping, exterior lighting and surveillance.
- The project is scheduled for presentation to the Minneapolis planning commission, with a request for a conditional use permit to vary the number of parking spots, square footage per unit and approval for site plan review.
- Minneapolis planning commission meeting is canceled.
- The Harvest Hills final construction plans and replatting are delivered to the planning commission.
- On the basis of the revised bid, the anticipated cost per square foot will be reduced from $87.13 to $74, decreasing project costs.
- The Anderson Corporation agrees to donate windows for the facility, saving an additional $40,000.

August 2000

- The Harvest Hills project is further delayed by the Coon Rapids city council, which denies the application for final plat review and extension into a conditional use permit area on grounds that the project would not allow sufficient parking for the existing Salvation Army Corps facility across the street from the project.

September 2000

- Hope Harbor construction plans go out for a bid.
- The Salvation Army replats the entire Harvest Hills project and resubmits it to the city of Coon Rapids.
- The Salvation Army appeals the decision of the planning commission to the city council, which denies the appeal.
- Plans are made to have the Salvation Army's attorney discuss this problem with the City of Coon Rapids attorney.

October 2000

- Hope Harbor bids are received from the invited contractors.

- A contractor is selected, contracts are finalized.
- The Harvest Hills project is granted full approval by Coon Rapids city council.

November 2000

- Initial closing with MHFA is planned, followed by groundbreaking at the Hope Harbor site.
- The Salvation Army hopes to begin groundbreaking for the Harvest Hills project.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Hope Harbor project and the service delivery model, please contact the project director:

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Operation Link, Catholic Community Services (Hudson County)

Sheltering and Engaging Multiply Diagnosed HIV-positive Homeless

Authors: Elaine Cohen, Chris Carroll and Maria Caban

Introduction

Operation Link is a Special Project of National Significance (SPNS) funded by the U.S. Department of Housing and Urban Development's (HUD) Housing Opportunities for Persons with AIDS (HOPWA) grant program. In August 1996, the HUD Office of HIV/Housing funded Operation Link through its HOPWA Multiple Diagnosis Initiative (MDI). Operation Link is an emergency shelter and support services demonstration program designed to engage and retain in services the hard-to-serve homeless, often on the streets, homeless persons diagnosed with HIV/AIDS and a severe chronic mental illness and/or addiction to alcohol or other drugs.

Located in Jersey City, New Jersey, Operation Link is a program of Catholic Community Services' (CCS) Hudson County Division. As such, it is an integral part of a developing continuum of housing and support services for homeless, multiply diagnosed individuals with HIV/AIDS in Jersey City. In addition to the Operation Link emergency shelter, the CCS continuum of programs specialized for persons with HIV/AIDS includes outreach services, transitional housing, plus permanent housing and residential end-of-life palliative care for persons with HIV/AIDS both of which are in development.

As an eight-bed shelter within a larger general emergency shelter setting, Operation Link often receives referrals from its general shelter population of single homeless multiply diagnosed individuals. In addition,

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Link receives referrals from local Hudson County social services and HIV medical care programs, substance abuse treatment facilities, and County Ryan White case managers.

Operation Link Model of Care and Services

The goal of Operation Link is to demonstrate that the traditionally underserved population of homeless people with HIV/AIDS and a chronic severe mental illness and/or addiction to alcohol and other drugs can be effectively linked to housing and other social services through an intensive service delivery model specialized to meet their needs. The goal is subdivided into two challenges:

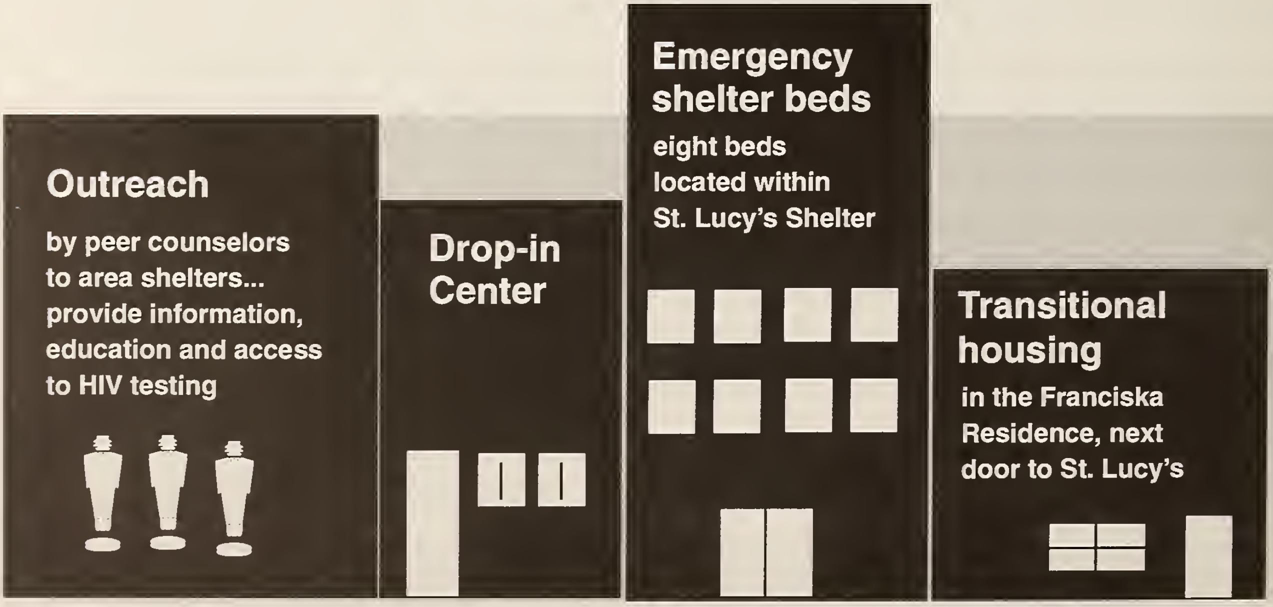
- To develop a service model that can effectively engage the hard-to-reach homeless multiply diagnosed person with HIV/AIDS through a risk-reduction low-demand and non-intrusive environment of care

- To participate in a cross-site national evaluation to determine the effectiveness of the program model and its effects on the critical dimensions of engagement and service utilization

Operation Link is composed of four integrated service components and, although the project represents a social service innovation for Jersey City's homeless population, each component builds upon and enhances currently existing community resources. This integration of existing services into one service continuum creates a highly coordinated model of intensive services for the homeless population diagnosed both with HIV/AIDS and a severe chronic mental illness and/or addiction to alcohol and other drugs.

The program implemented four service components. The first of Link's four service components is its outreach service. Although unable to implement its mobile outreach van due to regulatory limitations associated with medical services, Operation Link used its peer counselors to implement outreach to its Greenville Resource Center and area shelters. In addition to making target population clients aware of Operation Link services, the outreach component provided information, education, referral and access to HIV testing. Through this outreach, staff initiated relationships with clients that encouraged them to become more fully engaged in the program's continuum of housing and other social services.

The second service component is a drop-in center, located at the Operation Link shelter. Because of reduced funding in its original award, Link was not able to implement its originally proposed concept of



Operation Link has four components each of which builds upon existing community resources.

opening a drop-in center to the larger community. It remained available to Operation Link clients as a resource and socialization room, a meeting room for group events and resident community meetings, and a means for peer counselors to personally get to know the target population while discreetly and unobtrusively assessing their service needs.

The third component is eight reserved emergency shelter beds located within the larger St. Lucy's Shelter. The Link-designated beds are located in a separate room from the open dormitory shelter space and, unlike the regular emergency shelter beds, are available to participants 24 hours a day and include three meals. Clients can remain in shelter beds, and when ready, move into transitional housing.

The fourth service component is special AIDS transitional housing which is provided by Catholic Community Services' Franciska Residence located next door to Operation Link and the St. Lucy's Shelter. Operation Link clients have been able to be transitioned into this service component in a seamless service delivery manner.

Location

Link operates in Jersey City, New Jersey as a 24-hour, seven-day-a-week emergency shelter providing linkage to support services for homeless individuals with HIV/AIDS who are also diagnosed with mental illness and/or substance abuse problems. Jersey City is an urban center with a substantial homeless population, chronic affordable housing shortages and the second highest rate of AIDS cases per 100,000 people throughout 1998 among metropolitan areas in the United States. Jersey City's "1996-2000 Consolidated Plan" identifies the need for increased housing services for the homeless. The plan estimated that 50 percent of the city's unsheltered homeless population is dual diagnosed, with 11 percent of that population affected by AIDS-related diseases.

Services

Operation Link is designed to serve homeless men and women with HIV/AIDS who are also diagnosed with mental illness and/or substance abuse problems. The study population consists of all clients screened for eligibility and admitted to Link.

The low-demand, non-intrusive philosophy of care developed by the experienced Link team is especially designed to progressively engage homeless individuals who typically display a multiplicity of needs. As expected, those served are often actively in addiction on admission, typically lacking in stable social and familial supports, exhibiting prior episodes of transiency and housing instability and likely to shun sustained engagement with others. Evidence of low impulse control, problems with anger management and patterns of behavior that are likely to try the patience of and often elicit rejection from other shelter or social services systems are apparent.

In addition Operation Link serves both the larger social and medical services community dealing with this target population. Its work focused heavily on readying both the client and the social services system for each other. In the process of referring clients, this involved considerable work, to encourage greater levels of flexibility and tolerance among social services and medical providers who were called upon to serve this population.

Provider Team

Operation Link has several collaborators, all of which support and participate in the project.

- Medical and Social Services for the Homeless (MASSH) has on-site personnel for case management and medical referral for their clients enrolled in Link.

- Let's Celebrate provides a hot lunch and snacks for Link shelter residents

- Franciska Residence provides transitional AIDS housing to Link participants

In addition to these collaborators, Operation Link views the larger service provider community and the Ryan

White county case managers as critical to its success. Serving a target population with multiple needs from medical to mental health to addictions and entitlements, Operation Link staff were sure to develop and nurture good working relationships with community providers who would be called on behalf of clients in need.

Lessons Learned

The project, traditionally has several unique features expected to be especially effective in engaging homeless clients who have been difficult to engage or chronically unstably housed. Among those unique features are:

- Low demand, high tolerance philosophy of care that encourages progressive engagement of clients through a non-punitive, non-judgmental and non-intrusive stance toward service involvement and relapse.

- Recognition that change toward healthier life choices is incremental and non-linear, often marked by positive steps alternating with episodes of relapse.

- Concept of change that involved encouraging high levels of client personal choice, empowerment and self-direction in promoting and maintaining improved lifestyles and healthy life choices.

- Provider recognition of the need for commitment to the client throughout this approach-avoidance movement towards change.

- Absence of typical demand for abstinence when the client was not ready for change, although on-site substance use was prohibited.

- Modes of intervention which heavily rely on, encouragement and suggestion, building of trust, immediate transportation, use of peer counselors as integral program and client supports

Lesson # 1: Peers have a positive impact.

The use of peer counselors has proved to be an effective strategy for engaging clients and linking them to needed services. Having themselves been HIV-positive, at risk of homelessness, are in recovery, the peers are an effective bridge between the professional staff and the client, offering companionship and encouragement as well as knowledge of available services in the community. Peers are highly committed and dedicated to helping others to navigate the social service system and achieve a more stable, healthy and independent lifestyle. The use of peers does, however, require close ongoing professional supervision to assist them in to negotiating boundary issues, insuring adherence to a risk-reduction approach and/or encouraging a non-judgmental approach.

Lesson # 2: Learn ways to coexist with different services.

The project operates as a small, specialized HIV/AIDS shelter within a larger general emergency shelter. This creates both opportunities and challenges that can inform future replications of this model. For example, within one month of opening its doors, Operation Link was at full capacity and continued at capacity throughout its demonstration period. Being housed in a larger shelter enabled staff to identify HIV-positive clients within the general shelter population who could be placed on a waiting list for an Operation Link bed. It became apparent, that if wait-list clients were not engaged quickly, they would be lost to contact once a bed did become available. In order to remedy this situation, the general shelter and Link managers both agreed to set aside holding beds in the general shelter for clients awaiting admission to Operation Link. This arrangement enabled the peers to begin preliminary engagement and service provision that succeeded in retaining wait-list clients in service until an Operation Link bed became available.

The general shelter operates on an abstinence-based model, while Operation Link espouses a risk-reduction model of care. Close and respectful working relationship between the managers of each shelter accounted for the tolerance needed to implement the risk-reduction model of care. Even so, tensions were apparent, as identified in an ethnographic study between general shelter staff, who viewed Operation Link clients as highly privileged and subject to a too permissive approach, and Operation Link staff who were seeking to encourage client empowerment, personal choice and self-direction. Among the lessons learned is that communication needs to remain open and working relationships encouraged between staff of the two shelters to insure that tensions do not disrupt program implementation. One strategy to promote this was to provide cross training for peers who sometimes assisted shelter staff, and thus came to be seen as helpful partners.

Lesson # 3: Seize the opportunity to engage the client.
Although originally funded as a short-term emergency shelter (typically 30-45 day stay), Operation Link learned that many clients needed longer stays in the program's risk-reduction environment prior to transfer into an abstinence-based transitional or permanent housing situation. Premature transfer result in losing the client to the streets. Rather, Link staff learned that if clients struggling toward positive life changes were kept engaged in services and housed even beyond the traditional emergency shelter length-of-stay definitions, they could succeed in achieving more stable housing. The major lesson learned is that effective work with the hardest-to-serve person needs to seize every opportunity for engagement, create a flexible environment unconstrained by rigid rules of engagement that might drive clients away.

> The major lesson learned is that effective work... needs to seize every opportunity for engagement, create a flexible environment unconstrained by rigid rules of engagement that might drive clients away.

Lesson # 4: Relationships with community providers are critical.
In that the homeless, multiply diagnosed person with HIV/AIDS is often in need of multiple services, it is essential that the program staff maintain good working relationships with staff of community agencies. Peer counselors prove particularly effective in this regard, having prior knowledge of such services and being themselves known in the service provider community. Operation Link adopted a view of community service providers as their second target population, as customers who need to be nurtured and engaged to accept unconventional Link clients at a moments notice. Link staff maintain solid working relationships, so that when client need presented itself, staff could call on such relationships to secure a contact, an admission or an appointment for clients promptly, –even transporting clients to that appointment– as needed. In addition, Operation Link worked closely with the Ryan White county case managers, to avoid duplication of work and to insure that clients other needs (medical, mental health, substance abuse, etc.) were incorporated into treatment plans being made by those case managers.

Lesson #5: Get creative.
Multiply diagnosed homeless persons with HIV/AIDS often present behaviors which challenge the patience of staff, program administrators, and even other clients with whom they interact. Disappointments are inevitable as clients act out to sabotage their recovery, relapse or disengage from service, even after promising gains have been made.

Staff who seem to be most effective in dealing with the uncertainties of shelter life are those with a high tolerance for ambiguity, a willingness to not always know the answer and are comfortable with a certain amount of unstructured space in which clients can define their own direction. The latter suggest some of the key characteristics of staff who might prove most successful in working with this target population in a shelter setting. From an administrative perspective, staff and managers should be prepared, to assemble the shelter team and make decisions at a moment's notice when dealing with provocative or difficult behaviors.

One segment of clients have had multiple admissions to Operation Link and to the general shelter. Rather than being seen as failures, such re-admissions are seen as evidence of effective engagement of clients who understand that Operation Link's philosophy permit second chances and forgiveness of prior provocations. The philosophy of progressive engagement enables clients who relapse repeat chances to move toward healthier life choices and continue work on their personal issues through re-admission. Recognition that such clients require a flexible approach is essential to effectively working with this population.

Operation Link Chronology

March 1996

- Development team meets to design a program in response to Housing Opportunities for Persons With AIDS Multiply Diagnosed Initiatives RFP which would expand and complement CCS' existing HIV/AIDS services.

March-May 1996

- CCS' continuum of care for HIV/AIDS housing services discussed, needs assessment conducted, model drafted, program elements planned, community service provider linkages organized, letters of support requested and application completed. Proposed program includes evaluation component for quantitative and qualitative look at process and outcomes.

May 1996

- Application for funding submitted.

August 1996

- Notice of award received with a 25 percent reduction from the requested amount.

September-November. 1996

- Reduction in award results in revisions to program design.
- The number of designated shelter beds is reduced from ten to eight.
- The drop-in center is available only to Link residents.
- The frequency of outreach and the work hours of medical personnel and peer workers are reduced.
- The planned permanent housing renovation is dropped from the plan.

February 1997

- CCS and HUD sign contract.

March-April 1997

- Project director recruitment begins.

May 1997

- Project director hired.

May-June 1997

- Project director begins program implementation.
- Policy and procedure and staff training manuals developed.
- Planning meetings with collaborators held.
- Evaluator introduces the program director to the purpose and functions of the PSC and the multi-site evaluation plans.
- Evaluator's development of baseline and follow–up data collection tool proceeds.

June 1997

- Coordination of mobile outreach unit with local collaborator slowed by confusion among parties regarding responsibilities for hiring and supervision of staff. Link project director and collaborating program director work to establish a complimentary approach.

- Project director begins outreach to community HIV providers.

June 1997

- Project director begins recruitment of staff.
- CCS medical director contacted to assist in recruiting psychiatrist.
- Peer worker interviews begin.
- Recruitment of nurse begins.

July 1997

- Staff hiring.
- Nurse and one peer are hired.
- Peer worker begins training.
- CCS staff psychiatrist agrees to assume part-time Link position.
- Start dates of nurse and psychiatrist postponed until the details of the mobile unit's operation are established with collaborator.
- Donated mobile outreach unit arrives on site.
- A prospective peer worker is unable to accept the position because of income restrictions imposed by SSI. This uncovers the disincentive to work caused by income restrictions of entitlement programs.
- Nurse reconsiders employment due to salary.
- Plan to locate male dorm on the same floor as the female dorm raises an unanticipated security cost. Reconfigure shelter dormitory spaces to avoid cost increase.
- Project director begins preliminary scouting of sites frequented by drug users to be targeted by mobile outreach efforts. Shelter safety security officers (Jersey City police officers) familiar with the scouted areas caution project director about potential harm to both staff and vehicle in targeted areas.
- CCS Hudson County division director and project director conflict over street outreach strategies. Compromise reached when division director approves unanticipated cost of security officer doubling as vehicle driver.
- Police officer hired as mobile unit driver.
- Program evaluator continues to meet with project director discussing data collection tool, peer training, and IRB formation and composition.
- Project director, evaluator and CCS Hudson County division director attend all 1997 PSC Conferences and participate in multi-site SPNS group to develop core data elements.

August-September 1997

- Female peer applicant recently paroled reveals drug conviction on her application, which activates HR concerns. Hire delayed two weeks while parole officer is contacted for clarity about the nature of the charge.
- Peer is cleared for hire but states she is about to become homeless because of family move; project director arranges housing for peer in CCS emergency housing.
- Peer resigns when he receives SSI benefits which restricts income.
- Evaluator's training of peers is interrupted by personnel changes.
- Project director and CCS Hudson County Division Director report on project's status to Advisory Board.
- Harm reduction considered as model of care used in the Link program.

- Project director, CCS Hudson County division director and evaluator discuss the parameters of and implementation of a harm reduction model within a zero tolerance shelter environment.
- Project director and shelter director agree to work toward the use of harm reduction strategies in working with Link clients residing at the shelter.
- Two meetings are held with shelter staff to introduce harm reduction approach as the preferred approach used in working with substance abuse issues in Link program.

August 1997

- First meeting of Institutional Review Board occurs.
- First clients housed in shelter designated Link beds.
- Collaboration with Let's Celebrate is working efficiently to provide lunch and snacks to Link clients.
- Clients not connected with medical services are referred to Medical and Social Services for the Homeless through established link with MASSH staff posted at shelter once each week.

September 1997

- Referrals from local service providers fill shelter beds.
- Link-designated beds at capacity.
- Project director extends capacity to 15 beds to meet demand.
- A waiting list for Link beds is started.
- Peer hired.
- Link staff begin referring unconnected clients to medical care providers making referrals to Link for housing.

October 1997

- Full-time caseworker hired using private foundation grant.
- Female peer arrested for parole violation.
- Peer recruitment continues.

November-December 1997

- Operation Link's shelter bed census remains over contracted number.
- Principle investigator reduces the number of extra Link beds used to four representing a 33 percent increase over contracted number.
- Project director secures permission from shelter director to admit a maximum of two Link wait listed clients to the general shelter population in holding beds.
- Operation Link staff begin outreach to resident's in the general shelter population through informal contacts regarding HIV and testing.
- Project director presents case to principle investigator for changing the outreach effort from one targeting psychiatric clients to one targeting the medically underserved.

December 1997

- Second peer hired and begins training with evaluator on data collection.

January 1998

- Nurse practitioner with HIV experience is hired to provide education and outreach services.
- Nurse begins developing policy and procedure manual for medical interventions.

- The number of holding beds used in the shelter by Link candidates increases to accommodate the number of referrals from community medical providers.
- Project director and CCS Hudson County division director discuss ways to implement outreach van.

January-August 1998

- Unanticipated difficulties regarding licensure of outreach medical service delays start-up.
- Resistance of CCS medical staff administration to treat undomiciled clients delays start-up and raises questions regarding the feasibility of implementing the outreach van.
- High census in Link mitigates street outreach due to a lack of emergency housing available for those contacted.
- Due to emerging conflict between the project director and the executive director of the collaborating organization, the project director suggests the shelter director act as liaison to facilitate outreach operation.

April 1998

- Link physician hired to begin outreach to at-risk shelter residents and to develop medical protocols with nurse for van operation.
- Link evaluator resigns.

May 1998

- Physician meets with administrative medical staff to explain plans for street outreach.
- CCS director of program evaluation assumes responsibility for program evaluation component as new Link evaluator.

June-July 1998

- Nurse offers HIV educational presentation at shelter and begins street outreach contacts with peer.
- Ethnographers hired to observe Link operations, with particular emphasis on process for establishment of shelter rules.

September 1998

- Daily log designed by Link project director and evaluator to capture type and intensity of service offered to each client; completed by all Link workers on a daily basis to track service utilization patterns not captured in baseline and follow-up data instruments.

September –December 1998

- Discrepancies discovered in Link instruments and core data elements for baseline and follow-up instruments reviewed with ETAC and revised by local evaluator.
- Work begins to revise code book to conform to instrument revisions for ETAC QA review.
- Discussions with project director and CCS Hudson County division director initiated by evaluator to consider addition of control group through outreach component. Obstacles include concerns about staff safety in collection of data with homeless on the street, difficulty obtaining data using lengthy baseline instrument from those who might be intoxicated or high, barriers to implementing outreach component of program, and CCS Hudson County division director's concern about limited resources to collect such data.
- Decision made to forgo collection of data from control group.

October 1998

- Project director authorized to step up outreach without collaborator and without the mobile unit.
- Link nurse and physician begin regular outreach to general population of shelter resident's regarding HIV. This includes individual meetings and educational films and referrals to testing sites.

- Evaluator expresses concern about quality of data being collected by peer interviewers, with particular attention to missing data. Decision made to hire master's level CCS employee working in MICA Outreach and familiar with target population for data collection interviews.

December 1998

- Interviewer hired and trained by evaluator to collect baseline and follow-up data.

January 1999

- Project director, evaluator and CCS Hudson County division director attend PSC Conference in San Antonio.

February 1999

- Meeting held between project director and coordinators of Hudson County CCS HIV/AIDS service programs to discuss feasibility of collaboration on outreach efforts and to determine ways of using the mobile outreach unit for non-medical purposes.

February 1999—present

- Link census continues above capacity, the need for a waiting list continues, nurse outreach efforts expands to include visits to another local shelter, the mobile outreach van remains unused and the Link physician's employment status changes from per diem to as needed.

April 1999

- Coping, social support questionnaires recommended by ETAC and other questions included in Link local evaluation; approval requested and given by IRB chairman in consultation with IRB members.

June 1999

- Project director, evaluator and CCS Hudson County division director attend PSC Conference in Georgetown.

September1999

- Provider codes revised by project director and evaluator to insure completeness in database for QA review.
- Interagency linkages questionnaire designed to capture quality of linkages and satisfaction with services
- Project director, evaluator and CCS Hudson County division director attend ETAC- sponsored housing research paper workgroups at Arden House.

October 1999

- Third and final Link IRB meeting to formally approve additional coping and social support questionnaires added to local Link evaluation.
- Project director participates in panel discussion about Link operations at U.S. Conference on AIDS.

December 1999

- Project director invited to speak to HUD office workers (Washington D.C.) about real implementation of HUD-funded program.
- Hire of ethnographer to interview peer workers and project director for local evaluation paper on challenges and advantages of using peer workers.
- Interagency linkage/ satisfaction questionnaire mailed to more than 70 other providers.
- Suspension of acceptance of new Link referrals in anticipation of grant termination on.
- Suspension of baseline and follow-up data collection interviews.

January 2000

- Suspension of collection of daily service logs.
- Evaluator participates in All Titles Conference and Poster session re: Link.

April 2000

- Project director, evaluator and CCS Hudson County division director attend PSC Conference in San Francisco.

January-September 2000

- Completion of data cleaning, ETAC QA review process for multi-site database; data analysis completed; final HUD three year report completed.
- Evaluator and Project Director work collaboratively to interpret findings and prepare dissemination products.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by Operation Link, you are welcome to contact the project directly and request technical assistance.

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The Bridgeport Multiple Diagnosis Program, City of Bridgeport

Transitional Housing and Supportive Services

Authors: Stan DeMello, Michael McCarthy, Marinel Reyes-Medina and Stephanie Kim

Introduction

The City of Bridgeport has struggled to provide housing, community services and general assistance to its most needy residents, the homeless and economically disadvantaged, as the number of requests for these services has increased beyond capacity. Housing exists but is not affordable, accessible or safe for the homeless with special needs. Homeless individuals and families are rent burdened or must pay more than 30 percent of their income for rent and utilities. This problem is compounded by the impact of HIV/AIDS epidemic from which Bridgeport has not been exempt.

The Bridgeport Multiple Diagnosis Initiative (MDI) is designed to coordinate linkages with multiple AIDS service agencies to provide intensive outreach, emergency housing, transitional housing and supportive services to 100 MDI diagnosed individuals and their families in Bridgeport. The project provides cross training of service staff and coordination of systems of outreach, crisis intervention, treatment and aftercare. Clients must be homeless and formally diagnosed with HIV/AIDS and/or severe mental illness and/or a chronic substance abuse history to be enrolled into housing. The project has learned a number of instructive lessons on how to work with multiply diagnosed clients, a diverse group of providers and divisions of city government.

The Bridgeport Program Model of Care and Services

Location

The greater Bridgeport area is comprised of diverse communities along Long Island Sound, approximately sixty miles northeast of New York City. Wealthy communities are interspersed with poor communities.

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Through December 1999, the Connecticut Department of Public Health reported 1,100 cumulative cases of AIDS in Bridgeport, including 72 that were newly diagnosed. In addition there were 39 newly reported cases of HIV infection in Bridgeport. Many people with HIV/AIDS are struggling with homelessness, substance abuse and mental health problems.

Services

Three sites provide transitional housing for MDI clients: one facility for women with children (Alpha Home), one facility for single women (Bethel Recovery Center) and one facility for single adult males (Prospect House). The transitional living programs (TLPs) provide multiple services, including on-site residential case managers, treatment services, food, clothing, job readiness/vocational rehabilitation, life skills training, and peer mentors.

Provider Team

The Bridgeport Multiple Diagnosis Program brings together different partnering agencies to provide housing, case management and other services. Since different agencies have capacity and resources in differing fields and in order to provide the best services for multiply diagnosed individuals, it was necessary to bring all of these agencies to the table. The Connecticut AIDS Residence Coalition (CARC), a statewide organization based in Hartford, Connecticut has provided leadership in planning and development of supportive housing for people with HIV/AIDS and assistance to Connecticut's AIDS housing providers, all of whom are CARC members.

The MDI Housing Initiative Program in Bridgeport is a natural outgrowth of CARC's coordination and planning efforts. If it were not for CARC's involvement, it might have been more difficult to secure the interest and commitment of potential agencies in Bridgeport. CARC's positive reputation and initiative to convene several meetings of AIDS housing and service providers to identify needs of homeless individuals and families eventually lead to the decision to submit a proposal to HUD under the HOPWA SPNS MDI Competition.

Bridgeport MDI Partners

Alpha Home	Transitional housing program for families
Bethel Recovery Center	Transitional housing program for single females
Catholic Family Services	Project Director/Administration of Bridge fund and emergency shelter fund
City of Bridgeport	Administrator/Local evaluation
Connecticut AIDS Residents Coalition	Resource identification/Local evaluation
Evergreen Network	HIV support services and youth advocate case manager
Helping Hands Center	Substance abuse and vocational case managers
Prospect House/Regional Network of Programs	Transitional housing program for single males and mental health case manager

Historically, CARC collaborated with member agencies and partnered with the State Department of Social Services in applying for the HOPWA SPNS Competitive Grants. The decision to have the Department of Social Services as the lead applicant was based on the acknowledgment that a unit of government had more capacity than a community-based nonprofit, and was perceived as a stronger applicant. Also, units of government are potential sources of ongoing funding enhancing the incentive to partner with them. But since the housing models and support services offered by the Bridgeport HIV/AIDS Housing Initiative were focused locally, it made sense for the applicant to be the City of Bridgeport.

Originally, when the grant was written, the day-to-day management of the program was going to be provided by a project director stationed at Alpha Home, a transitional living site, but when that agency's leadership changed, the project sponsors decided to house the project director at another agency. Catholic Family

Services (CFS), one of the sponsor agencies contracted to administer the Bridge and Emergency Fund (funds to give to program graduates for moving expenses and to get individuals off the street during outreach), volunteered to take on this task. They were a large organization with a strong infrastructure and had been a CARC member in good standing for a number of years.

Lessons Learned

Lesson #1: Regular interaction accomplishes what contracts cannot.

Program developers anticipated that boundaries and roles might become blurred because so many agencies were involved in the project. Tension or conflict was bound to emerge—and it did. The lack of agreement on service delivery models and role clarity made it more difficult to resolve differences in leadership/management style. For example, since the project director did not have oversight and leverage over the project sponsors like a fiduciary agency would, it was more difficult to resolve conflicting policies and procedures being used by the agencies operating the three housing sites.

> Since MOAs are not legally binding, the committee felt that working together... to create common policies would result in the desired outcome.

The project was able to resolve issues in a constructive and successful way. The first step was the formation of two committees: a steering committee and a policy committee. The steering committee consists of all of the stakeholders including executive directors from the project sponsors and representatives from Department of Social Services and the Greater Bridgeport AIDS Care Consortium. Agency participation is mandatory, as stipulated in sponsor contracts. The committee meets monthly to review program operation, policy issues, client data and other programmatic functions in order to facilitate the coordination and implementation of the project. Prior to these meetings, many of these agencies had never worked together beyond participating in common forums. The success of the project was dependent upon creating close working relationships, and the steering committee fostered the development of these relationships and goes beyond work on the Bridgeport MDI project. The development and growth of these peer-to-peer relationships has created additional partnerships, such as joint applications for Ryan White and other federal funding sources.

Secondly, a policy committee consisting of the project director and the executive directors of the three transitional living programs was established to develop new uniform policies and procedures for the collaborative project. This committee meets once a month and its work has focused on creating: (1) client guidelines, rules and regulations, (2) staff guidelines and rules, and (3) ways to ensure that CARC standards are being met in the provision of housing and support services. CARC developed its Standards of Care for providing housing and services to those who have HIV/AIDS to ensure quality and consistency in service delivery. CARC members are required to incorporate these standards into their programming. The policy committee reports their recommendations and reformulations to the steering committee.

The policy committee has gone beyond its original purpose and has evolved into a problem solving and support group. When difficulties arose in selecting and deciding what instrument could be developed to help guide work across agencies, especially given the unique division of program tasks/responsibilities, creating memoranda of agreement (MOAs) between agencies was explored as a solution. The policy group, however, felt that developing common policies applicable to all three housing sites could substitute. The development of MOAs requires extensive amounts of work for agencies and takes time away from their ability to provide services. Since MOAs are not legally binding, the committee felt that working together and deciding by consensus to create common policies would result in the desired outcome.

These steering and policy committee meetings have greatly strengthened the relationships/linkages between agencies. The regular interaction between program directors and the project director accomplishes what contracts and MOAs cannot. It was these relationships/linkages that allowed the group to bridge differences in agency philosophies/procedures.

Another way in which this kind of conflict was resolved was by identifying and providing technical assistance to one of the project sponsors. One of the housing sites did not have much experience in rendering professional services and therefore was not familiar with or trained in providing appropriate and effective services to people with HIV/AIDS. Examples include the lack of a personnel manual and the lack of choice in programming in regard to religious attendance. Additionally this agency did not have the financial capacity to continue operations without the MDI grant. The City of Bridgeport, as the grantee, had to revise the overall project budget and reallocate funds so this agency could improve financial and organizational capacity.

The lessons learned in facilitating collaboration include:

- Establishment of interagency communications protocol, definition of staff roles, and clear lines of authority will serve as a solid foundation for good working relationships.

- Compatibility in leadership/management styles of executive/program directors, agency capacity, experience/sophistication, and a successful history of collaboration are important considerations before inviting agencies to be part of collaborative projects.

- The number of years in operation is not an indicator of an agency's capacity, quality of services, and ability to collaborate. Additional assessments need to be done including a review of quality assurance reports, financial statements and consumer feedback. An informal telephone survey of peer agencies will also provide valuable information, particularly an agency's history of collaboration.

Lesson #2: Zoning barriers have a domino effect.
In providing housing, the project encountered major difficulties with zoning regulations. The original property location of the women's house was claimed through eminent domain for redevelopment. While the agency received financial assistance in relocating, they had to confront the challenge of finding a suitable, appropriately zoned building and dealing with unwelcoming neighbors. During this time of uncertainty over the new location the project did not accept new referrals for the house.

The family house also experienced difficulties. For example, Alpha Home was about to purchase a building with state AIDS bond funds. The building was in need of renovation but before proceeding, the agency needed to secure a zoning exemption. Area zoning required two parking spaces per unit and a certain square footage of landscaped yard. Providing the required landscaped yard and parking spaces would compromise the amount of housing the agency intended to offer. Alpha Home was unable to secure this exemption because of opposition from the community.

Another zoning issue arose with the housing site for single males. The agency was initially unable to find a legal three-family house that would allow up to 12 unrelated residents. When an appropriate facility was finally found, the landlord had rehab/cash flow issues that stalled the timeframe and pushed back occupancy of the house. It was then discovered that the house was legally a two-family house, thereby only allowing eight unrelated residents. Zoning barriers have had a domino effect, negatively affecting administrative efforts, as well as outreach, thus impacting the number of clients to be served and delaying hiring of a full complement of staff.

The project has consulted and asked for assistance from the Hartford-based Connecticut Fair Housing Center and a law firm in Baltimore that are both experienced in zoning issues and are poised to aid the project in defending against any enforcement action.

Even though the City of Bridgeport was the applicant/recipient of the HOPWA-MDI grant and although its Central Grants Office was heavily involved in the implementation and evaluation of the project, other departments within the city government should have been informed of the project. Timely and accurate information about the project could have been disseminated to the planning and zoning department beforehand and their cooperation and support should have been solicited prior to implementation. This might have mitigated some of the zoning problems.

Lesson #3: Linkage starts from the ground up.

Before providing services in a community, it is important to make the project known and to market it in the broader community. This can be accomplished by participating in local provider forums serving people with HIV/AIDS, and meeting with key service providers. The project coordinator invested much time at the beginning of the grant period towards these activities. But while many agency executive directors had pledged their support to the project, the program directors and line staff often knew little about the project or their own agencies' commitment.

Strong linkage development also involves establishing working relationships with non-MDI agencies. The project coordinator, as well as the grant manager, became active participants in the local Ryan White consortium group: Greater Bridgeport HIV Care Consortium, The Regional Council for the Homeless, and the Continuum of Care Group, whose work focuses on providing services for the homeless. This groundwork and continued presence on these advisory collaborative boards have strengthened these linkages, facilitating referrals of clients from related community initiatives. For example, when it was necessary to bring in focused technical assistance to one of the housing sites, the Bridgeport Program was able to recruit and contract for services with one of the agencies that also served on the board.

Cross training

Another way in which relationships have flourished between staff at different agencies is through cross training. The case managers and administrative staff from partnering agencies have participated in training that covers topics such as working in supportive housing, documentation, HIV, grief and loss, mental health and substance abuse. The training has encouraged service providers to discuss issues that cut across disciplines as well as familiarizing and preparing staff for issues they might not deal with regularly. These trainings have allowed case managers whose work and skills may focus in one particular area, such as substance abuse, to understand all of the different perspectives that are important in a client's care, enhancing relationships between agencies and also services rendered.

How to handle differences in operational timelines

One of the difficulties with the project was that two of the housing sites were delayed in start-up while one was not. It would have been much easier to refer and offer housing and comprehensive services when all three sites were operational. Even if one project was ready before the others, it would be better to have that site wait until the other sites were operational. However in this case, Bethel Recovery Center could not wait, as funds were needed to sustain operations. Now that the other sites are functional, the funding for Bethel has been depleted, however the program was able to reallocate funding so Bethel's operations would continue and end when the other agencies finished. The continuation allowed the project to offer the full complement of services.

A possible solution to this and other problems is for the project to have in place a contingency plan. Alternative housing models with accurate cost estimates for project development and management would serve as a back-up in case the original project suffers a long delay or has to be abandoned because of regulatory, environmental, or financial reasons.

Bridgeport MDI Project Chronology

May 1997

- CARC and sponsoring agencies, Alpha Home, RNP/Prospect House, Helping Hand Center, Catholic Family Services of Bridgeport, Bethel Recovery Center, and Evergreen Network begin to meet to discuss submitting HOPWA SPNS application.

July 1997

- City of Bridgeport and CARC submit HOPWA grant.

November 1997

- MDI grant announcement from HUD—$1.2 million.

December 1997

- First meeting with Columbia University regarding ETAC's role. Principal investigator selected and local evaluator position announced.

March 1998

- Steering Committee comprised of sponsoring agencies develops criteria/advertises for coordinator's position.
- Interviews held for position of project coordinator.

April 1998

- Bethel Recovery starts to operate transitional housing program for single females.

May 1998

- City enters into subcontracts with partner agencies.
- Alpha Home secures State of CT AIDS bond funds for $600,000 for construction of eight units of permanent housing. This funding is used as a cash-leveraging match to the HOPWA MDI.

June 1998

- MDI coordinator hired.
- Outreach efforts begin. Case management positions are advertised.

July 1998

- Architect hired for rehabilitation and construction. Must appear before the zoning board of zppeals for waiver on parking and landscape variances.
- House director takes maternity leave.
- Substance abuse specialist is hired.
- Social work intern aides in program mangement.

September 1998

- Local evaluator selected and announced.

October 1998

- Policy committee proposes to address issues surrounding multiple housing policies and procedures.
- Steering Committee decides not to hire full compliment of staffing until all housing options (single males, single females and families) are on-line/operating.

November 1998

- Alpha Home agrees to rent property to serve families until new site or zoning can be resolved.

December 1998

- Request for zoning waiver is denied. Neighbors oppose site because of concentration of social service agencies in area. Key staff member resigns.
- Director returns from leave.

January 1999

- New home director begins.
- Project coordinator takes maternity leave.

February 1999

- Residential case manager is hired.

March 1999

- Project coordinator returns from leave.

April 1999

- Policy committee develops standard policy to cover all housing options and continues to address areas of concern.
- Project coordinator reports problems with management/capacity.

May 1999

- CARC conducts quality assurance review.
- City intervenes on management. Makes recommendations to Board of Directors on agency capacity and program development.

June 1999

- City instructs Board of Directors to contract with outside agency to provide management assistance.

July 1999

- HUD approves request to use HOPWA funds for management assistance. A provider of such services is identified.

August 1999

- Project coordinator resigns.

September 1999

- Housing case manager is hired.

October 1999

- Transitional Living Program for families opens.

November 1999

- New project director hired.
- Transitional living program for single males opens.

December1999

- Substance abuse case manager resigns.
- First male client enters transitional living program.

January 2000

- Vocational case manager is hired.
- Mental health case manager is hired.

February 2000

- First family enters transitional housing.

March 2000

- First family reunification occurs in family transitional housing.

April 2000

- Substance abuse case manager is hired.
- Central Grants Office submits first round of client data to ETAC.

June 2000

- Transitional living program for single men is issued a zoning violation for operating in a residential zone. Response to City of Bridgeport states program is operating within the letter of the law.
- Youth advocate case manager is hired.

July 2000

- ETAC attends monthly MDI Steering Committee to administer linkage template.

August 2000

- Project evaluator resigns.
- Connecticut Fair Housing Center begins research to assist in the defense against zoning citation.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the Bridgeport Mutiple Diagnosis Project, you are welcome to contact the project director and request technical assistance:

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Montefiore Medical Center: Culturally Competent Services/ Bronx, New York

Culturally Competent Mental Health Care

Authors: Mark Winiarski, Emily Beckett and Maria Caban

The information is based on interim findings from the first four years of a five-year demonstration project. Final results of the evaluation will be available Fall 2001 upon completion of the project and data analysis.

Introduction

The Culturally Competent Integrated Mental Health HIV Care Program consists of several elements — first, an HIV mental health team integrated with primary care at a community health clinic on 161st Street in the South Bronx. The team is comprised of a psychiatrist working half time and social workers trained as psychotherapists. The concept of integration includes (a) the creation of a multidisciplinary treatment plan; (b) writing in a common chart, to facilitate communication; (c) regular multidisciplinary treatment team meetings and (d) continual interdisciplinary communication regarding patients.

Second is the provision of culturally responsive care, which involves training providers in cultural issues. Project components were selected to erode barriers to care for clients, who were mostly persons of color with histories of substance abuse or the sexual partners of substance users. Finally, the last element is a program of psycho-educational seminars, attempting to attract persons who would not avail themselves of traditional mental health services.

In the clinic, the program is called the Wellness Track/Camino al Bienestar.

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While some other SPNS projects and experimenters have tested new models adapted to the needs of these persons, there has been little acceptance of these innovations by dominant systems. The Montefiore project hoped to provide mental health services that were culturally responsive to persons of color, in contexts that did not shame or stigmatize.

Location

The project operates within Montefiore Medical Group, a network of primary care sites operated by Montefiore Medical Center. The treatment clinic is the Comprehensive Health Care Center (161st Street/ MMG) in the South Central Bronx. For project evaluation purposes the two comparison clinics are the Comprehensive Family Care Center (Morris Park/ MMG) and the Family Health Center/ MMG.

Services

The program provides services to persons of color in the Bronx, New York, the northernmost borough of New York City. The program addresses the needs of this population as reflected in the demographic statistics of the state and the effect of HIV/AIDS. Seventy-seven percent of the 1.2 million citizens of the Bronx, are persons of color and the per capita income is $10,514. The cumulative adult AIDS case rate was 2,274/100,000 in year 2000. That HIV/AIDS has become a condition with a majority of persons of color strongly argues for the need to test a model of care to meet the explicit needs of African-American and Latino communities.

The Wellness Track/Camino al Bienestar Program has several components. First, psychiatric and psychotherapy services always attempt to be culturally appropriate and non-stigmatizing. Montefiore's patients face a variety of barriers—linguistic, cultural, economic—which the program seeks to address through the provision of client-centered, culturally-sensitive services in both English and Spanish.

Second, a series of seminars is open to all clinic patients. Seminars consist of psycho-educational meetings meant to introduce information to patients in a nonthreatening, nontraditional manner and to serve as a gateway to enrollment in SPNS mental health services for the hard-to-reach patients and/or those who underutilize mental health services. These weekly seminars are conducted in both English and Spanish; topics have included "Secret Keeping in the Family" and "Substance Use and Prevention Relapse."

Third, the Patient Advisory Board (PAB) meets regularly and provides an opportunity for patients to comment on the workshop/series program and to designate topics they believe are of interest to the larger HIV/AIDS patient community. Meetings serve as a forum for patients to voice concerns about the general functioning of the clinic. Views are shared on cultural issues and their impact on medical and mental health care.

Cultural responsiveness is a major feature of this program's intervention. The mental health workers, together with the research team, regularly take part in training meant to sensitize them to cultural issues within a clinical context. Training includes reading articles and participating in discussions, sharing cultural vignettes, attending presentations by guest speakers, and keeping a journal of their own experiences with cultural bias within their clinical practice. At least one hour of each week's training is dedicated to cultural responsiveness. Around the table are people who are gay, straight, Latino, black, white, male, and female. Through these activities, providers continually increase their knowledge of cultural issues and foster the experiential element of cultural awareness.

Provider Team

The project's team consists of a psychiatrist and several social workers. Members of the team provide psychotherapy in English and Spanish, and psychopharmacology. They work side by side with the medical staff and psychosocial unit and are available on-site for quick referrals, walk-in appointments as well as consultations with the primary care physicians. In addition, the team is responsible for monthly case conferences at the HIV medical team meeting. Team members work closely with the clinic HIV coordinator in fostering a psychosocial context in which to better aid the patients. Their focus is integrating mental health care to the overall HIV medical care of patients in a culturally sensitive manner.

The Montefiore Logic Model

The Montefiore logic model is a schematic of the project's hypothesis that culturally compentent, integrated mental health services will result in higher quality of life for multiply diagnosed minority patients.

Patients

Definition
Adults
HIV positive
Primary care at Montefiore

Characteristics
Poverty
Minority status
Marginalized
Substance abuse
Victims of trauma

Intervention

Culturally competent integrated mental health care

(Psychotherapy and Psychopharmacological Services)

Proximal Outcomes

More referrals to mental health

More visits to mental health providers

Increased patient satisfaction with services

Distal Outcomes

Higher quality of life reflected in:

Improved mental health status

Less substance abuse

Lower rate of seroconversion

Better general health

An integrated treatment team cares for patients. The team is comprised professionals with three specialties: two physicians who specialize in HIV/ AIDS care, a psychologist or social worker who provide both psychotherapy and substance treatment intervention, and case managers who attend to concrete services and entitlements issues such as housing, disability payments, and food stamps.

Added to the integrated treatment team is a patient care program that offers positive, non-stigmatizing pyscho-educational, supportive and mental health services. The program, offers culturally specific packages of mental health/ substance abuse and other psychosocial interventions that are (1) culturally valued; (2) perceived as non-stigmatizing and (3) assist patients not only with HIV-specific issues but with other social related issues, such as substance abuse, spirituality, parenting and planning their children's futures.

Study Sample

Two groups were evaluated. The first group encompassed patients who obtained services but declined to be part of a formal assessment procedure. There is limited information on this group, such as age and ethnicity, drawn from clinical records. The second group is volunteers, with signed consent forms, drawn from the population HIV/AIDS adults who are active patients at three of the Montefiore Medical Centers' outpatient clinics (meaning they have kept an appointment at the clinic within the past year). They were recruited through flyers in English and Spanish distributed at the clinics and through referrals from providers. The project's research assistants carry pagers in order to allow for interviews to be conducted on a walk-in basis. Participants/subjects in the program are paid $10 for baseline interviews, $15 for first follow-up interviews and $20 for second follow-ups. The research sample is 162 persons; most assessed three times over one year.

Lessons Learned

Lesson #1: Medical systems and patients respond differently.

Responsive mental health care is defined as convenient, high-quality, and respectful of a patient's culture. The integration of mental health services has been successful, with psychotherapy being a fully integrated component of care at the clinic. At this time evaluation indicates that both the medical system and the patients individually responded in different ways to the program.

For example, of 543 patients eligible for referral to Wellness Track services, clinical staff referred 260 (47.8 percent) which is almost one of every two patients. The next analysis of data will indicate how well clients responded but initial observations indicate a remarkably large response.

> That HIV/AIDS has become a condition with a majority of persons of color strongly argues for the need to test a model that offers....

Lesson #2: Work around unforeseen barriers.

One of the project goals is to have patient cases discussed by the integrated team with integrated treatment plans written and included in the patients' charts. The meeting is to be attended by project staff as well as clinical medical, psychosocial, and other providers.

This objective met with substantial barriers. The major barrier was the adminstrations' focus on increased productivity by primary care providers, which made additional meetings very expensive in terms of lost patient encounters. As a result, the goal of an interdisciplinary meeting to discuss patient care plans was not met. Instead, the program held one meeting per month on case discussions. The SPNS-funded providers made a substantial contribution to those meetings. Communication between project staff and other clinical staff was accomplished through this meeting, and through the patients' charts and informal corridor conferences.

Lesson #3: Pyscho-educational seminars were ineffective.

The Wellness Track psycho-educational seminar series was a good idea that was tried and substantially failed. The goal was to provide "nontraditional, culturally appropriate psycho-educational and supportive services" that would provide information and help recruit persons into mental health care.

One issue, raised almost immediately, was that if the seminars were limited to persons with HIV, attendance in a public place would disclose their status. As a result seminars were opened to all clients. At the end of each seminar attendees were asked to complete feedback forms asking for an anonymous disclosal of status. This attempt to obtain nformation was unsuccessful.

Beginning at the end of Year 1, psycho-educational seminars were provided by the project on a weekly basis in an attempt to recruit people to mental health care. Attendance was uniformly poor (from none to five attendees and typically two-to-three) even after suggestions from the Patient Advisory Group were incorporated. Seminars were held in Spanish as well as English, refreshments were available, the scheduling was changed to determine if some time periods were more attractive than others. Topics were diversified; some targeted Latinas or women generally. After a trial period of experimentation during Year 3 and an examination of the situation, the seminars were discontinued.

There were several hypothesized reasons for the failure of the Wellness Track Program's seminars: first, as with any group regardless of culture, there is little time for optional activities such as health seminars. Patients have many appointments both at the clinic and with various city agencies for insurance, housing and public assistance. While many patients expressed interest, they did not attend. Second, patients visit the clinic infrequently (every 3- 6 months), and perhaps did not see schedules of Wellness Track activities. A mailing to all HIV-positive clinic patients was considered but the overriding need to maintain the confidentiality of their diagnosis precluded a specialized mailing. Compilation of a group of clients who wanted mailings became a labor-intensive and time-consuming chore. As an alternative, a table in the lobby offering information on HIV-related topics is periodically staffed by the project.

Lesson #4: Cultural responsiveness must be consciously and continuously articulated.
HIV/AIDS has tragically become part of the fabric of the inner city, yet persons of color there face health care systems that often fail to meet their cultural needs. Recent research indicates persons of color significantly underutilize medical and psychosocial HIV services. That HIV/AIDS has become a condition with a majority of person of color strongly argues for the need to test a model that offers an integrated health care team with specific emphasis on culturally competent care, and a program of non-stigmatizing, culturally appropriate psychosocial and mental health services.

Montefiore Medical Center has had the opportunity to provide mental health services to the Bronx population for years via SPNS grants. Experience and lessons learned from previous programs made it possible to enhance the provision of mental health services with this current grant. Past experience taught that much of standard mental health psychotherapy, specifically and psychiatric care based on Western European models is culturally inappropriate for persons of color. Moreover, these services provided in fairly rigid medical-model systems discourage utilization by persons whose lives are marked by poverty, lack of opportunity, the need to wrestle with unwieldy entitlement systems, encounters with law enforcement and child welfare systems, and substance abuse.

A lesson learned in previous programs was that in order to meet the explicit needs of persons of color; this SPNS project had to make cultural responsiveness a consciously major, and continuously articulated, theme of care. If cultural responsiveness were relegated to an afterthought, represented by episodic inservice programs, but a conscious major theme, then mental health care would be conducted as it has for decades, with the usual discouraging results.

The program, therefore, had the following elements:

- A team of providers, who were, in effect, self-selected because of their commitment to work in the inner city.
- Clinical team members who represented a variety of cultures and were, for the most part, bilingual in Spanish and English. Team members were white, black, Latina, gay, straight, foreign-born, U.S. born, male and female ranging in age from mid-20s to 60.
- A weekly hour of attention to cultural issues in HIV mental health care including discussions of reading from pertinent books of articles, presentations by speakers with expertise in areas of cultural competence, and discussion of cultural vignettes from actual cases at the clinic. The knowledge gained at these meetings was then shared with colleagues at the clinic through individual discussions with providers, weekly social services meetings, and monthly coordination meetings.
- A newsletter was also published by the Wellness Track at irregular intervals and distributed to clinic staff. Publication of this newsletter met some barriers from staff who said their mailboxes were often stuffed with announcements and other papers, and that they didn't often read what they had received.

> ....an integrated health care team with specific emphasis on culturally competent care, and a program of non-stigmatizing, culturally appropriate psychosocial and mental health services.

Lessons learned included:

- Primary care clinic staff members, regardless of their ethnicity, tend to believe that they are already culturally knowledgeable, and are typically unwilling to set aside additional time amid their already busy day to consider these issues.
- An essential issue in cultural responsiveness is the acknowledgment of invisible monoculturalism in medical and mental health care.
- Individual providers must concern themselves with their unconscious racisms, which are often demonstrated in subtle ways with clients.
- The issue of cultural responsiveness is very radical and is viewed by some as significantly threatening.

Lesson #5: Follow Patient Advisory Board (PAB) suggestions with direct action.

Although the creation of a Patient Advisory Group seemed to be a good idea, it has been a very disappointing experience and as a result, the group was temporarily discontinued. The PAB functioned for about two years, from mid-way Year 1 through mid-way Year 3. During this time it was difficult to get volunteers, but the program's social workers persevered and meetings with three to six persons occurred. Then attendance dropped off to the point that meetings were not viable. The major reason for the attrition, according to the social workers, was that nothing was done to ameliorate problems, such as poor telephone service at the clinic, which had been identified by advisory board members. After several months of providing advice that was not followed, group members stopped attending. Participants have stated that they made all the proposals/ suggestions/comments they could think of and more meetings would no longer add value to the project. Due to the lack of implementation of the suggested changes, participants did not longer see the PAB as a serious forum for their voices to be heard.

Lessons learned include:

- Project developers and administrators should make it clear to the advisory board that their comments about non-project issues may not receive a response.
- If project and system administrators want to communicate a message of caring and importance to the advisory groups, they must send representatives to the meetings. These representatives should be individuals who have the power to respond to complaints and concerns.

Lesson #6: Be flexible in the face of change.

During the five years of this SPNS project, the system in which it operated saw major and continual changes in the table of organization, personnel, and organizational culture. In order to continue project staff needed to be flexible and adapt to the changes. A few changes were:

- The SPNS project was borne within a primary care network based in the inner city with a large Medicaid clientele. During the project cycle the main medical center merged with a private-practice model organization that had little inner city exposure.
- There was significant turnover of medical staff in the clinic.
- Clinic psychosocial staff changed during the project's existence. For example, a very supportive social worker died during the early phase of the project.

Montefiore Project Chronology

This chronology of implementation and development demonstrates the steps and length of time involved in developing program components. The chronology also presents the barriers project staff encountered and the process involved in overcoming them.

October 1996

- Project receives funding.

November 1996

- Received Institutional Review Board (IRB) approval.
- Montefiore Medical Center begins to consolidate the socially conscious primary care network with a private-practitioner medical group network that focuses on privately insured patients.

December 1996

- Approval of funding amount.
- Recruitment for staff begins.

April 1997

- First social worker is hired and begins working at the treatment site.

May 1997

- Second social worker is hired.
- Wellness Track intervention program officially begins.
- Evaluator pilots self-administered surveys.

June 1997

- Four part-time research assistants begin at the main site and at the control site.
- SPNS staff invites providers to nominate patients as members of Patient Advisory Board (PAB).

August 1997

- Two research assistants resign to return to school. Remaining assistants become full-time to staff each site.
- Half-time psychiatrist starts at treatment and control centers.

September 1997

- Social worker resigns.
- Wellness Track workshops begin on a weekly basis. Workshops are offered in both English and Spanish.
- Wellness Track has information table at health fair. The intervention is introduced.
- Medical director of the primary care network resigns. Director was supportive of the mental health program but the continuing administration wishes to divest itself of mental health activities. Program loses a major source of referrals as a result.

October 1997

- Evaluator resigns.
- Research assistant assumes duties of evaluator on a temporary basis.
- Replacement social worker hired. Social worker meets with administration to discuss whether SPNS staff could provide psychosocial and cultural content at staff meetings.
- First Patient Advisory Board (PAB) meeting.

November 1997

- Social worker meets individually with providers and other staff to explain services provided by and the goals of the SPNS project.

December 1997

- Presentation of Wellness Track program at social service meeting.
- HIV physician with a large caseload of patients resigns. There is a drop in referrals to Wellness Track.
- Provider questionnaires are distributed at clinics. Few are returned.
- Improvements in evaluation made by upgrading database system from Paradox 3.5 to Access. Data cleaning and codebook development.

January 1998

- Memorandum to all staff providing detailed information on Wellness Track (including staffing, services provided, eligibility criteria) and requesting staff assistance in regarding survey and nominations for the PAB.
- Presentation stressing integration of care is made to representative from 30 clinics. At conclusion, the medical facility administrator advises that referrals can be made away from the site.
- HIV physician at the control site resigns. Project loses significant number of referrals to the study because the bulk of HIV positive cases follows the physician or is referred to another clinic.
- The project's plan to have psychiatrist lead cultural discussions — a major component of the project — is rejected by the medical director because of pressure to improve physician productivity.

February 1998

- A social worker dies suddenly resulting in loss of program support and referrals.
- Flyers inviting patients to sign up for support groups are posted and given to providers.
- Search for evaluator continues.
- Research assistant is hired to work at control site.

March 1998

- HIV physician at treatment site resigns.
- HIV coordinator at another control site resigns impacting referrals and caseloads.

April 1998

- Project moves administratively to the Department of Psychiatry.
- HIV coordinator hired at treatment site and agrees to meet monthly to review cases with an emphasis on psychosocial and cultural issues.
- Research assistant resigns; new research assistant is hired.

May 1998

- Social workers have a second meeting with administration to review integration of Wellness Track program.
- Social workers plan distribution of cultural bulletins on a monthly basis to all clinic staff.
- Meeting with the medical group HIV director to discuss Wellness Track program in anticipation of medical director's departure.
- After seven months, the position of evaluator is filled.

- Research assistant begins part-time.
- Project data submitted to evaluators.

June 1998

- Medical Director resigns. Results in drop in number of referrals to Wellness Track program.
- Project closes registration of new HIV patients at the clinic due to insufficient number of medical providers with expertise in HIV.

July 1998

- Semi-structured interviews are piloted at the sites; instrument changes from self-administered to interview format.
- Database changes from Paradox to ACCESS and SPSS.
- After two-month delay, research assistant is placed at control site.

August 1998

- Meeting with medical providers focusing on cultural issues.
- Full-time research assistant resigns.
- Focus group for African-American males is attempted to further examine barriers to services and underutilization issues. One person of six confirmed attendees appears.

September 1998

- Group therapy begins for men and women who speak Spanish and mothers with children. Both groups are subsequently discontinued due to low attendance.
- HIV coordinators start at control sites.

October 1998

- It is determined that HIV-positive patients new to clinic are to be referred out due to staff shortage and turnover.

November 1998

- Full-time research assistant begins.
- Social workers present Wellness Track program and cultural component at Yeshiva University.

December 1998

- Staff retreat held to identify goals and objectives of intervention and evaluation.
- Staff decides to suspend the SPNS Patient Advisory Board (PAB) due to low turnout. Medical group states intention to convene a system-wide PAB program.
- Medical group begins its Patient Advisory Board with seventeen participants at the first meeting.

January 1999

- Medical director hired.

February 1999

- Discussion with new medical director regarding the freeze on registration of HIV patients. Medical director indicates policy will change and new providers are appointed with HIV expertise.

April 1999

- One of the two therapists resigns, leaving one full-time social worker and a part-time psychiatrist.

May 1999

- Office space continues to be problematic, as the only office available is on a different floor from where the majority of the patients are treated.
- The research assistant loses his office to an intern and is unable to cover the site on a full-time basis.
- Evaluator resigns after one year.

July 1999

- New HIV coordinator begins. She dictates that all HIV positive cases are to be maintained on site and referrals to the Wellness Track intervention increase.
- Search for evaluator continues.
- Project moves to new offices.
- Project physician leaves.

September 1999

- Evaluator on another grant accepts offer to work on SPNS part time.

November 1999

- Social worker leads workshop on cultural competence and presents at the U.S. Conference on AIDS in Denver.
- Presentation made at the American Public Health Association annual meeting in Chicago.
- Consultant hired to assist in comparing old SPNS data with current SPNS data.

January 2000

- Three presentations made at the Ryan White CARE Act All-Titles Meeting in Washington, DC.

March 2000

- SPNS staff addresses the national AIDS Update Conference in San Francisco.

April 2000

- Memo sent to medical group officials informing them of the project end.

May 2000

- Presentation made at the American Psychiatric Association annual meeting in Chicago.

July 2000

- Staff written article on responding to distrust in the medical system is published by Focus: A guide to AIDS Research and Counseling.

August 2000

- Project physicians leave.
- Clinical aspects of project end.
- Clients are referred either to a psychiatrist who serves the clinic part-time, or to other community clinics.

September 2000

- Project evaluation continues with research assistants interviewing subjects.

October 2000

- Staff members address the U.S. Conference on AIDS regarding project findings.

December 2000

- Research supervisor leaves. New statistician is hired on a part-time basis.
- Article manuscript on the SPNS project is submitted to a peer-reviewed journal.

January 2001

- Research staff begins calling project clients to determine if they availed themselves of other mental health care after project end.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the Montefiore Medical Center you are welcome to contact the project director and request technical assistance:

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The Fortune Society, ETHICS 3 Coordinated Health Care Program

Engaging and Retaining HIV-positive Ex-offenders in Primary Medical Care

Authors: Althea Brooks, Jennifer Lin and Narene Malcolm

The program is located in Manhattan, NY. This information is based on interim findings from the first three-and-a half years of a five-year demonstration project. Final results of the evaluation will be available upon completion of the grant cycle in Fall 2001.

Introduction

Traditional medical models do not effectively engage and retain HIV-positive ex-offenders and their families in primary and HIV–specific ambulatory care. Historically, this population encounters numerous barriers in attempting to receive medical and social services. Many ex-offenders are unable or unwilling to access services. Without proper access to the appropriate services, the physical and mental health of ex-offenders and their families will suffer unnecessarily.

The Fortune Society's ETHICS 3 (Empowerment Through HIV Information, Community and Services) Coordinated Health Care Program provides a humane transition from prison to the outside community for HIV-positive ex-offenders. The project successfully linked HIV-positive inmates with primary health care providers prior to their release from prison. The program also assists participants in the transition from incarceration to a productive re-entry into the community. One of the goals of the program is to provide discharge planning that is designed to effectively link HIV-positive inmates to medical care and supportive services upon release. Another goal is to ensure that HIV-positive ex-offenders and their

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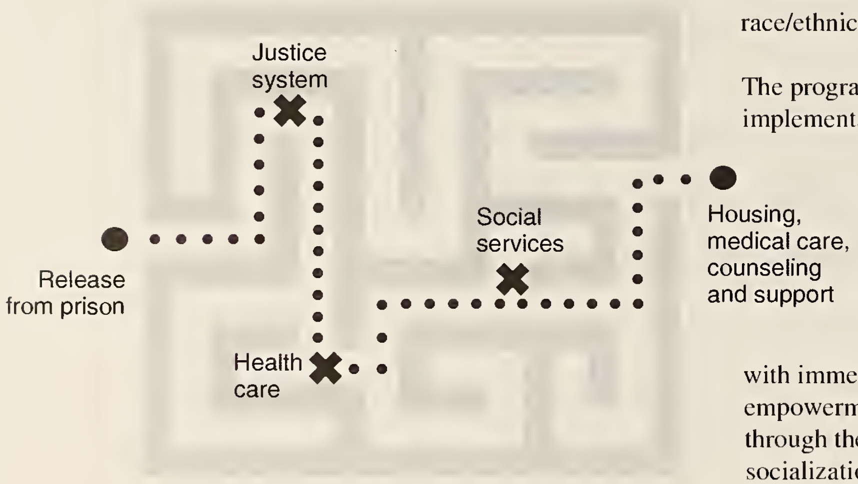
family members have access to and are retained within a coordinated, linked and integrated health care service delivery system, including both medical care and the supportive case management needed for consistent participation in treatment.

Location

The Fortune Society, Inc., is a non-profit organization located in lower Manhattan and has advocated for the rights and welfare of inmates and ex-offenders since 1967. The ETHICS Unit, and in particular the Coordinated Health Care Program (CHC), is devoted to serving the needs of HIV-positive inmates and their families.

Services

ETHICS 3/CHC, an intensive case management program, is based upon the idea of an integrated service delivery model. This model (1) addresses clients' hierarchy of needs; (2) provides holistic, wrap-around services in an easily accessible setting; (3) provides a supportive and health-promoting social network for clients; (4) promotes behavior change by providing services for each client based on the client's own stage of readiness to change; (5) provides competent services and improves engagement with clients by employing peers (criminal justice-involved, substance abuse history, HIV positive, and/or similar race/ethnicity) as service providers.



Peer workers help client navigate the maze of institutions and agencies

The program has been successful in its implementation of an innovative program model. The CHC program model provides ex-offenders with continuity of contact from prison to the street, a family-focused approach to service delivery, and partnerships between Fortune and networked medical care facilities. CHC also provides clients with immediate and continuing access to health care, empowerment advocacy and reduced social isolation through the creation of drug-free opportunities for socialization.

The first priority of the project is to help ex-offenders achieve basic stability including housing, a source of income or public assistance, and primary medical care. The project provides intensive case management, involving crisis intervention, counseling services and referrals for services for clients and their families. Case managers assist clients in developing individualized specific goals, objectives and treatment plans. The success of intensive case management is attributed to the staff's ability to arrange direct access to services both within and outside Fortune. Another reason for the program's success is the staff's own experience negotiating the same system of institutions and agencies.

One goal of the Coordinated Health Care Program is to provide clients with a supportive, health promoting, drug-free environment where clients can socialize and network. Fortune designated a lounge area for CHC clients only. Clients may gather in the lounge from morning to early evening, have lunch, socialize, and share information. Regular group activities are planned and clients are encouraged to participate. For example, CHC staff organizes frequent trips to the movies or a local bowling alley. On weekends clients can go to museums, concerts and other events and places they would not usually attend. Through these group activities and the clients being together, information is shared and exchanged in very informal ways. Also, through these activities, the staff has been able to assist clients in improving their social skills, which ultimately leads to a smoother integration into society.

Case Management System

Clients are recruited for the ETHICS 3/Coordinated Health Care program through Fortune's outreach at prisons, jails and shelters. Some clients are referred to CHC by other agencies and others walk in to Fortune for general counseling. Upon release from prison or jail, clients who qualify for the program begin an intensive case management program. Clients' needs are assessed using a newly created tool – an early intervention and assessment form. This form allows the case manager to concisely evaluate the client's immediate needs. Assessments are revised every two months with client input. Participants are referred to service providers relevant to their specific needs. All clients are provided with an initial medical referral. Additional areas of referrals include: financial benefits, housing, substance abuse counseling, MICA services, psychotherapy, food resources, educational and vocational services and day treatment programs. Clients are escorted to their referrals by a CHC staff member or peer counselor/educator. Confirmation of acceptance and/or attendance and continued participation is monitored and recorded by the case manager. Case managers have established working relationships and collaborate regularly with Fortune service providers. This enables the case managers to follow-up with service providers regarding each client's appointment schedule and health status.

Once the client's immediate crisis is addressed and initial health needs are met, the case manager's focus shifts to assisting the client in remaining connected to primary medical care and to continue productive reintegration into the community. In addition to a case manager, clients are assigned a support counselor to assist them in the stabilization process. The client also attends support groups facilitated by the counselor. The Fortune Society offers ten support groups within the health services unit. There are also several groups available throughout the agency's other units.

State prison inmates tend to possess a greater resolve and motivation to change their lifestyle, probably because they have been institutionalized for significantly longer periods within a highly structured environment.

Lessons Learned

Lesson #1: Consistent contact increases enrollment.

At the inception of the project case managers encountered numerous challenges in their attempts to provide discharge planning to inmates scheduled to leave prison. One problem the program initially encountered was the inability to maintain contact with inmates who had been identified as eligible for the project through monthly prison outreach visits. Case managers would find that a significant number of inmates were transferred to different correctional facilities and that they often did not maintain contact with the program afterwards. In response to this problem, the program implemented monthly written correspondence with inmates to supplement prison visits. By maintaining regular written correspondence, the project found it was better able to keep track of inmates who had been transferred.

An interesting trend discovered during the project's attempt to engage inmates from Riker's Island (a city jail) was their low rate of enrollment compared to inmates recruited from state correctional facilities. The reasons attributable to this pattern are threefold. First, most detainees at Riker's Island are not as stable as inmates from state correctional facilities. It was found that inmates from Riker's generally lack the commitment to turn their lives around. State prison inmates tend to possess a greater resolve and motivation to change their lifestyle, probably because they have been institutionalized for significantly longer periods within a highly structured environment. Thus, state prison inmates enrolled in the program at a much higher rate. Second, the majority of detainees at Riker's Island are being held indefinitely while they await final dispositions on pending criminal court cases. Many of these individuals are referred to Fortune's Alternative to Incarceration unit (ATI) for court advocacy intervention. However, many of them eventually receive state prison sentences as a final resolution of their case. Finally, until most recently, Riker's Island had a long-standing policy of releasing inmates at 4:00 a.m., dropping them off in front of a high crime and drug activity area. (Some inmates are now being released around 2:30 p.m.) Also, Riker's Island, unlike state prisons, does not require an inmate to secure an address prior to being released.

These three factors led to minimal participation in the Coordinated Health Care program by inmates at Riker's. The staff at CHC has instituted a more aggressive approach in its recruitment of Riker's Island inmates. One strategy implemented by CHC staff is to ask staff from other Fortune projects not funded by SPNS who also work with inmates at Riker's to refer inmates to the ETHICS 3 program. In addition, increased coordination and extensive discussions with social workers at the facility has led to more detailed and involved discharge planning. The CHC case managers, with the permission of the inmates, now obtain contact information from inmates prior to their release. Specifically, case managers obtain telephone numbers and addresses of family members and friends of each identified inmate during initial outreach visits. Such information affords CHC case managers the opportunity to visit and call the inmate's family members and friends in the event the inmate does not contact Fortune upon release.

Lesson #2: Collaboration increases access.

Another obstacle faced in providing discharge planning to inmates was difficulty in obtaining medical documentation from the Department of Corrections. This documentation is crucial in order for the inmate's case manager to secure housing and benefits prior to the inmate's release. By engaging the institutional parole officers and counselors in this process, the project is better able to obtain the medical documentation necessary for effective implementation of discharge plans. This collaborative effort proved instrumental in enabling the case managers to provide better services to their target population.

Lesson #3: If a program component is not working, re-evaluate to find a solution.

One of the criterions for participation in the program is that ex-offenders' family members must be willing to participate in the program and access health services through ETHICS 3. Prior to enrollment, potential program participants are informed of the family involvement component and agree to this condition. However, family members have not participated in the project as much as had been anticipated. Upon the inmate's release, case managers have found that the families of individual inmates are not willing to participate in the program. Reasons identified for this lack of participation include:

- participants' relationships with family members have deteriorated beyond repair;

- family members are engaged in other programs and/or receive services from a provider they are comfortable with;

- family members will offer support but at a distance; and

- clients have not disclosed their health status to their families.

The project has not been able to identify any overwhelming reason for the lack of family participation in the project; there are client-specific situations that have been identified, but no overall trend.

The Fortune Society has implemented several initiatives in an attempt to engage participants' family members into the program. The project has had several family oriented events such as picnics, holiday parties, children's parties, and completion ceremonies. Project staff has made home visits for the sole purpose of assisting and engaging family members.

Discussions with staff of a similar project revealed that they have encountered similar challenges. A questionnaire was developed and administered to project participants to ascertain how Fortune might better engage and serve family members. The project discovered that the suggestions made by the participants had already been attempted. To date, the project is still reevaluating this component of the intervention. Different strategies need to be implemented to increase the level of family involvement in the program.

Lesson #4: Clients would rather choose their own health care provider.
The project was designed to provide medical services through a linkage agreement with the Institute for Urban Family Health (The Institute). Clients enrolled in the project were to receive all medical services through The Institute. As the project evolved, case managers at CHC found that several participants did not want to be referred to The Institute. Some participants and their family preferred to remain with existing providers or ones that are located in their neighborhood. Others chose to utilize the services of medical providers who had been recommended to them by other inmates and friends. Consequently, Fortune staff developed contacts with the various medical providers being utilized by clients. The project concluded that Coordinated Health Care staff had to expand its focus on case management and follow-up with each client's existing health care provider and not solely The Institute. Collaborative relationships have been established with these providers in an effort to facilitate communication between the providers and the project. Through these relationships, the project has been able to minimize the wait for initial appointments.

Fortune Society's ETHICS 3 Coordinated Health Care Program has been successful in providing an intensive case management program which links HIV-positive ex-offenders to primary health care and other services. The program has faced many challenges that required revaluation of the program model and making adjustments in the intervention. With the exception of the difficulties encountered by CHC case managers and staff in engaging clients' family members into the program, the staff has been able to use these challenges as learning tools and has established new strategies to address these concerns. The staff at Fortune continues to re-evaluate the family component of the program and remains hopeful of finding innovative ways to increase clients' family involvement in the near future

ETHICS 3/CHC Project Chronology

October 1996

- Grant award received, project start date.
- Ongoing meetings held to discuss the evaluation of the project.
- Ongoing meetings held with institutional parole officers and counselors at correctional facilities.
- Corrections personnel are consulted with respect to inmate movement, transfers, and other vital issues, such as inmate availability.
- Monthly outreach visits are made at five prisons.
- The project utilizes the Client Admission Booklet as its intake form. This booklet has been previously pilot tested and approved for use in the Latino Discharge Planning SPNS program.

November 1996

- Meeting held to expedite processing of entitlements. Fortune staff are able to expedite the clients' access to Medicaid and/or Public Assistance.
- Outreach efforts to numerous agencies and health fairs throughout the city.
- Initial negotiations take place regarding cross training, referral and integration of services. An outside college conducts the first of a series of focus groups at Fortune.

December 1996

- Project director hired.

January 1997

- Procedure for referrals developed.

- Ongoing program activities commence: training and orienting of peer counselors, outreach to inmates through jail/prison visits, discharge planning for inmates, case management for released inmates, identifying possible referral sites and transmitting program information to referral sites and service providers.

February 1997

- No referrals were made to the Institute because the first clients reside in transitional residential milieus that mandate the use of other medical providers. Therefore, new linkages are sought with housing facilities that do not impose such restrictions on their clientele.
- Three of four direct service lines have been filled for the project.

March 1997

- Linkage agreement executed to provide HIV specific and primary medical care to program clients and their families.
- Fortune works with consultants to define the equipment and facilities needed for in-house video conference capabilities.

April 1997

- Case manager hired.

May 1997

- Outreach worker and discharge planning coordinator meet with superintendent to establish monthly outreach visits to the facility.
- Arrangements made with the correctional facility for weekly presentations.

June 1997

- Medical point person in the infectious disease unit at the correctional facility is identified. He agrees to collaborate and assure the consistent continuum of care for patients who have been rearrested and will remain in the city jail system.
- Program staff conduct a two-hour video conference session. The presentation is telecast to other correctional facilities.

July 1997

- Staff visit an outside drug treatment program to establish a referral process for inmates being released.

August 1997

- Fortune submits a non-competing continuation application to HRSA.
- Project director resigns. Immediate oversight for the project is temporarily reassigned to ETHICS Director.
- Case manager is hired.

September 1997

- Project director hired.
- Meeting to facilitate housing referral process for releases.
- Program staff conduct a two-hour video conference session. The presentation is telecast to other correctional facilities.

October 1997

- Case manager resigns.

November 1997

- Appointments scheduling protocol revised.
- The new system identifies a patient service representative as the contact person for scheduling appointments. This new system takes effect on December 1, 1997.

December 1997

- Memorandum of agreement with an agency to conduct an evaluation of Fortune's ETHICS 3 program during its second year of operation.
- A major housing referral source informs Fortune staff that they are filled to capacity, and would not be accepting referrals until further notice.

March 1998

- CHC case manager hired.
- Representative of the AIDS council visits The Fortune Society to establish referral linkage.

March – May 1998

- Evaluators review medical charts for 12 current and former CHC clients.
- Evaluators find that the average length of clients' engagement in healthcare services at Hillman is 79.5 days. They also find insufficient information on the qualitative aspects of clients' experience with healthcare services.
- Fortune is awarded a three-year contract from HRSA under the Ryan White Comprehensive AIDS Resource Emergency Act Title I.

April 1998

- Discharge planning coordinator contacts parole access counselor at Willard DTC to discuss lull in referral process. CHC staff is informed that Department of Parole would no longer approve temporary and emergency housing that The Fortune Society secures. Instead Willard DTC parole officers would be releasing inmates to shelters.
- Arthur Kill Correctional facility pre-release coordinator visits office to establish referral process. Agrees to refer Staten Island AIDS task force referrals to Fortune.

April 1998

- Fortune collaborates with evaluator to revise intake booklet. The revised intake booklet integrates data elements that are required for the multi-site evaluation project.

April – May 1998

- Evaluators begin survey of clients and a comparison group using a questionnaire. Elements of interest include socio-demographic information, health functioning and healthcare utilization.

May 1998

- Staff turnover at the Institute has impeded the ability to secure appointments for clients.

June 1998

- Discharge planner and prison programs administrator visit Fortune to establish a referral process.
- Fortune develops an instrument to collect a subset of CDQ elements, those addressing risky behaviors and drug and alcohol use.
- Fortune submits a non-competing continuation application to HRSA.

July 1998

- Fortune staff meets with two housing providers to secure a linkage agreement to enable Fortune's clients to reside in their facilities.

August 1998

- Charts reviewed for a sample of ten HIV-positive patients enrolled under the Ryan White Program. They find that the average length of clients' engagement in healthcare services is 166 days.

October 1998

- National search for a full-time director of research and evaluation is conducted.
- Case manager resigns.

November 1998

- Case manager hired.

December 1998

- Director of research and evaluation hired.

February 1999

- Fortune starts implementing new intake booklet.

June 1999

- Fortune submits round one data.

August 1999

- Fortune resubmits round one data set in response to the quality of assurance review.

September 1999

- Certificate of confidentiality issued by HRSA expires 9/30/01.
- Enrollment of subjects into the CHC study is approved. Collection of all data resumes.

November 1999

- Fortune resubmits revised round one data set, incorporating corrections on an Access 97 database.

December 1999

- HRSA project officer and ETAC mentor conduct site visit at The Fortune Society.

Further Information and Technical Assistance

If you are interested in obtaining further information about ETHICS 3 CHC, please contact:

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Native Care: HIV/AIDS Integrated Services Network,
National Native American AIDS Prevention Center, Oakland, California

HIV/AIDS Care for Native Americans

Authors: Paul Bouey and Stephanie Kim

This piece describes an innovative program, Native Care: HIV/AIDS Integrated Services Network, which provides HIV/AIDS services to HIV-infected American Indian (AI), Alaska Native (AN), and Native Hawaiian (NH) individuals. Native Care, a SPNS -funded program, addresses the unique cultural, spiritual, and traditional dimensions of these native populations. The Native Care project has encountered numerous constraints/difficulties while implementing their program and this piece attempts to relay some of these barriers as well as lessons learned. This article also highlights a few of the issues that make it difficult to offer services to this population.

Introduction

The main component of the program is the provision of case management services, based on the Ahalaya case management model, which utilizes a free standing, central model of service delivery and an extensive network of service providers. This type of case management service is better able to address the very broad diversity of needs found among AI/AN/NH HIV/AIDS clients. The model possesses two principal structures that incorporate native-specific elements: linkage framework and case management procedures.

The linkage framework consolidates access to medical, mental health, spiritual, social, emergency, and educational services. Case managers establish affiliations with other care giver agencies and access those services as needed by clients. Unique to the Ahalaya model is a foundation built on cultural, spiritual, and traditional healing dimensions. These characteristics offer clients greater support and access to information than afforded by non-native programs. In addition, this same cultural/spiritual paradigm is made available to

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the wider community, and particularly to non-native caregivers, through training programs administered by case management staff.

The Ahalaya Project

Unique to the Ahalaya model is a foundation built on cultural, spiritual, and traditional healing dimensions. Such characteristics offer greater support to clients and contribute vastly to the program's success. All other aspects of the program are built upon this foundation. Additionally, this same spiritual/cultural paradigm is made available to the wider community, and particularly to non-native caregivers.

Case management procedures prescribe a plan by which case managers interact with clients. Case managers conduct client assessments, work with clients to develop care plans, make and follow-up on referrals to other service providers, monitor client compliance with referrals and related activities, and advocate for clients in their relationships with other agencies and providers. Ahalaya case managers also provide or facilitate access to traditional/cultural services. One of the more important elements of the Ahalaya model is the flexibility to work with clients in virtually any setting, allowing the case manager to maximize access to the clients.

Location

The Native Care project is administered by the National Native American AIDS Prevention Center (NNAAPC), Oakland, CA, and consists of a network of nine Native- American specific (American Indian, Alaska Native, Native Hawaiian) HIV/AIDS case management sites located around the country. These service sites are located in Oklahoma City, Tulsa, Kansas City, New York City, Minneapolis, Phoenix, Chinle (Navajo Nation), Honolulu, and Maui. Each specific project site acts as a subcontractor to NNAAPC, and implements actual case management activities for its site while collecting evaluation data. NNAAPC acts as the administrative center and oversees the implementation and evaluation of these local programs.

Population and Need Analysis

The unique needs of this population make it difficult to provide services. Many cultural, historical, and ethnic differences exist within the AI/AN/NH popilation that keep clients from engaging mainstream service programs. A long history of conquest and genocide, as well as current conflicts associated with tribal sovereignty, create an environment that fosters mistrust and fear. These barriers, in fact, constitute major problems for clients and impede their ability and desire to seek services. To compound these problems, the 1990 US Census (1993) describes an American Indian/Alaska Native (AI/AN) population that is predominantly urban (56.2 percent; D'Angelo, 1996; Snipp, 1996), has a lower life expectancy than the general population, higher rates of poverty and unemployment, and lower rates of educational attainment. Native Hawaiians (NH) exhibit similar patterns, with greater rates of poverty and low income, higher mortality rates, and lower rates of educational attainment in the lower and higher grade levels (US Census, 1992).

Reluctant to seek medical and social services through conventional mainstream routes, native populations in this country have few alternatives since there exists a scarcity of native-specific programs that offer services. Access to general health care through the Indian Health Service (IHS) is limited by the service's role as a provider of last resort and its restriction to reservation-based populations within the 33 reservation states. Even in some of these communities estimates suggest that less than half of eligible AI/ANs use these services (Burhansstipanov and Dresser, 1993). Commensurate with these IHS limitations, the IHS has severely downsized its AIDS office. In general terms, the rural native population appears also to have reduced access to HIV diagnosis and treatment, and health care staff appear to lack experience with current recommended HIV/AIDS treatment practices (CDC, 1998). Urban populations, making up the majority of the population, experience even more extreme conditions, receiving less than 1.2 percent of the IHS annual budget to support a network of 34 urban clinics (Indian Health Service, 1997).

With this experience as a backdrop, one can envision how these circumstances can result in an HIV-positive AI/AN/NH being even more reluctant to enter into appropriate services. This disinclination is further intensified by the lack of funding for programs that cater specifically to AI/AN/NH with HIV/AIDS. There exists only one source of funding for programs of this nature, the SPNS Program that supports only demonstration projects. No ongoing funding programs support these services on a continuous basis. Other Ryan White titles do offer alternatives, but low AIDS numbers, low capacity to develop acceptable program proposals, and tribal sovereignty often preclude attempts to access these sources.

Why is there not more funding to provide services for these populations? One potential contributing factor to this problem may be the apparently low prevalence/incidence of HIV/AIDS in this population. According to CDC data (CDC, 2000), as of December 1999, 2,131 (1,743 males, 358 females, 30 pediatric) AIDS cases and 742 (550 male, 183 female, 9 pediatric) HIV infections have been documented. However this number may inaccurately represent the extent that this disease has impacted this population.

Part of this inaccuracy of a true count of those AI, AN, NH infected with HIV can be attributed to the HIV reporting/surveillance system. The burden of HIV infection among American Indians /Alaska Natives must be viewed in the context of the national surveillance systems. HIV data are the more relevant in today's treatment venue, but HIV reporting is not universal, nor has it been in use for very many years. In fact, the state with the largest number of natives and the second highest annual rate of AIDS cases, California, lacks an HIV reporting system. It is likely, therefore, that there are many more native individuals infected with HIV, but since the system does not track HIV cases universally, potentially large numbers of individual cases fail to appear in any statistics.

Misclassification is another reason why the number of HIV-infected AI/AN/NH may be higher than reported (e.g., Conway, 1992; Lieb et al., 192; Metler et al., 1991; Thoroughman et al., 1996). For example, a health care worker may assume a Native American client is Hispanic because of the person's Spanish surname. Staff also may classify a Native American as white or black due to appearance, without further questioning. Situations occur, as well, in which native clients misreport their own ethnicity to deflect documentation of native populations. In Oklahoma, the second largest native population state, racial misclassification of natives in the state STD surveillance system resulted in adjustments of up to 67 percent for gonorrhea and 36 percent for chlamydia (Thoroughman et al.,1996). Currently it is unknown to what extent HIV/AIDS rates need adjustment.

...the resources assigned to these populations are insufficient to meet the real needs.

In addition to these more general issues, reporting of any surveillance data whatsoever from IHS facilities to states is very problematic. Nearly all IHS Service Units (96.3 percent) responding to a recent needs assessment survey (ITCA, 1999) reported that tribes within their jurisdictions did not report HIV/AIDS data to the unit office. Essentially all Tribal Health Department respondents (94 percent) indicated that they do not report HIV/AIDS data to the IHS, the state, the county, or the CDC. Obviously, the data is very inadequate. Combining these problems, the scale of underestimation is quite substantial.

Recognizing that HIV/AIDS data are not adequate indicators of infection risk in this population, more can be learned when supplementing this data with surrogate indicators. For example, national 1997 data indicate that AI/AN rates for chlamydia, gonorrhea, and syphilis are the second highest of all race/ethnic groups, led by only the rates for African Americans. Simultaneously, national rates for primary and secondary syphilis for natives continued to increase since 1990 while those for all races decreased (CDC-DSTDP, 1999). Exacerbating this situation are overwhelmingly higher substance abuse and substance abuse-related morbidity and mortality rates for AI/AN than those for all populations (IHS 1998). Higher rates of poverty and lower rates of educational attainment contribute further to this bleak picture (US Census, 1993).

The Native Care project attempts to overcome the barriers encountered by these individuals by offering high quality native-specific case management (Barney and Duran, 1997; Bouey and Duran, 2000). The Native Care project, however, has not been able to accomplish its goals due to inadequate funding. The difficulties and few successes the project has experienced during the last three years offer some insight on possible strategies for future initiatives or lessons learned.

California, the state with the largest number of natives and the second highest annual rate of AIDS cases, lacks an HIV reporting system. It is likely, therefore, that there are many more native populations infected with HIV than appear in current prevalence data.

Lessons Learned

Lesson #1: There is a need to change legislation.

What becomes evident about offering more routine population-specific HIV/AIDS services is the need to change public policy as legislated in the Ryan White CARE Act. This action is comparably difficult, because without the compelling numbers to document the extent of the problem in this population, significant policy changes are less likely to occur. Universal reporting of HIV cases would certainly help the situation, or even improvements in the implementation of race classification, but such changes will be slow to develop. Conversely, the results of the Native Care SPNS evaluation might enable changes or modifications to ensure that appropriate funding for HIV/AIDS services reaches the native population.

Facing reality and knowing that the time and effort required to change legislation or usual surveillance system procedures is immense, it becomes more productive to focus on what kinds of changes or activities can be made within the current context.

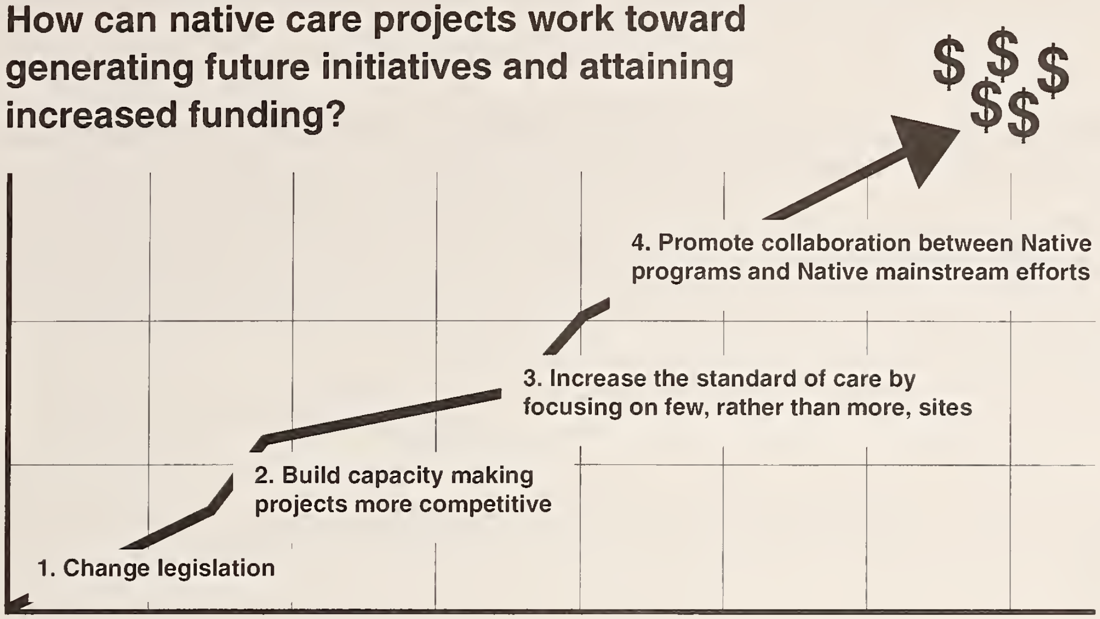
Lesson #2: Build capacity to make sites more competitive.

Since the reauthorization of the Ryan White CARE in year 2000 did not incorporate any changes to increase access to funding for native programs, the most logical strategy is to increase the capacity of programs to access monies in the existing titles. This effort requires two courses of action. First, Native communities will have to assume a more proactive role on Ryan White Councils. This change requires an increase of knowledge and skills to work on these Councils, developments that can be managed through a capacity building or technical assistance program. Second, many Native communities will have to increase their proposal writing abilities. This capacity expansion requires a breadth of knowledge, ranging from the interpretation of Requests For Proposals, to use of national and local epidemiological data, to program design, and ultimately to development of strong written documents. Similarly, this action can be assisted with formal capacity building programs, designed specifically to address the native communities.

Lesson #3: Focus on few rather than more sites.

One of the primary barriers encountered by the Native Care Network has been inadequate financial support to achieve the goals and objectives as defined at the start of the program. Inadequate funding has resulted in compromised care, as well as program redesign. This funding dilemma has had the hardest impact on the case managers, the vast majority of whom can work only part time. These dedicated individuals focus on the provision of optimal care and expend more time working with clients than they are funded to do. This commitment causes much frustration and considerable turnover among case management staff. In addition, case managers have to balance their extensive client responsibilities with nearly as extensive SPNS evaluation requirements. These problems, and grant requirements, suggest that it may have been more appropriate to

How can native care projects work toward generating future initiatives and attaining increased funding?



focus on fewer sites and expend more energy and efforts in only those locations. For example, supporting a full time case manager at a few sites may have resulted in a higher level of network success. Conversely, such a strategy also would have eliminated care for a large number of native HIV-infected, who would not have had entry to comparably focused and accessible care.

Lesson #4: Collaborate between native and mainstream efforts.

Another suggestion for future initiatives would be to promote intra-native program cooperation and cooperation between native and mainstream efforts. Examples of such approaches exist already. The current Navajo Nation project exemplifies the potential of multiple programs cooperating and organizing around a single issue. This project has encountered and overcome various obstacles, and the model stands as an important strategy for tribal communities. Similarly, successful examples of native and non-native cooperation also exist. Project sites in Hawaii are housed within the mainstream AIDS service organizations. The native case managers are supported with SPNS and other funding, and they provide care for native clients. These programs have been particularly successful, given the effort of the case managers and the awareness of the primary organizations. In Tulsa, one of the original Ahalaya sites works independently of, but is housed in, the building of the Title II Tulsa Cares project. Case managers from the two organizations work closely on common clients, as do the Ahalaya site and Care Point in Oklahoma City. In these two instances the collaboration is much more limited than that in Hawaii, lacking the strong financial component, but even this restricted level of funding support (i.e., rent) and the operational cooperation constitute good examples of the opposite end of the spectrum of this model.

These models offer an alternative strategy to implement programs, and even if the collaboration is stronger in terms of accessing Title I or Title II funding, some potentially serious compromises are required of the Native programs. Unless the project can stand alone and link with a mainstream AIDS Service Organization, the native project might have to become a component of the ASO and lose its unique qualities. The Hawaii examples are critical exceptions to this dilemma, but such success requires tremendous individual strength and diligence to the needs of the population. Before any such agreements were reached, guarantees would have to be secured that would ensure the native quality and character of programming. Preparing for this type of collaboration is an issue, too, that could benefit by capacity building assistance.

Native Care Project Chronology

February 1997

- Grant award received, but at reduced level. Proposed program and staffing redesigned to accommodate changes in funding level. Reduce case management sites, case manager/staff FTEs and salaries. Eliminate site visits, training and technical assistance programs, and modifications to goals and objectives are implemented. Funding level also required that NNAAPC move its physical location.

- Subcontractors continue case management work, but at reduced levels. Sites continue working with linked partners and attempt to expand local networks.

May 1997

- Move to new physical location.

June 1997

- SPNS-ETAC meeting in New York. Informal formation of a native caucus.
- Initiate discussion of all-native project case manager training for use of evaluation instrument. Submit letter to SPNS proposing training and requesting information regarding possibility of funding to support effort.

July 1997

- Letter sent out to other project sites requesting additional information for SPNS regarding case manager training

September 1997

- Workshop presentation of SPNS project data at Proceedings of the National Conference on Community Systems-Building and Services Integration.

November 1997

- Notice of Grant Award from HRSA to support case manager training. Program to occur in conjunction with subsequent SPNS-ETAC meeting in Jan 1998.
- Technical assistance request to address problems at one of the native project sites regarding access to Ryan White Title I and II resources. This site, as well as other minority-based providers, was denied support by the local administration.

December 1997

- HRSA unable to offer support for project site problem because issue is a local one.

January 1998

- SPNS-ETAC meeting. Conduct case manager training with participation of ETAC. Considerable time spent addressing needs of participants. Develop a good foundation for a focused training at a later date.
- Continuation application requests funding to support full-time case managers at all project sites, to conduct site visits, and to conduct training for evaluation and grant writing.

February 1998

- Notice of grant award. Modifications made to program to accommodate grant award: support staff at two locations only; no site visits or training.

March 1998

- Initiate use of new process evaluation forms for subcontractor sites. Two forms for each month to be completed and submitted with narrative reports. One form documents activities with each client, and second documents monthly proposal submissions, new service linkages, and information dissemination activities.
- Preliminary release of baseline evaluation instrument to subcontractor sites for review and piloting.

April 1998

- Project director/evaluator and NNAAPC executive director meet with Navajo Nation AIDS Office representatives and project evaluator in Albuquerque, NM, to configure an Memorandum of Agreement (MOA) for case management support and data sharing.

Aug 1998

- Submission of first baseline data set to monitor submission system (e.g., sending files, data cleaning, ETAC response, etc.). Only six individuals represented in this file.

October 1998

- Project coordinator resignes from NNAAPC. Project coordinator vacancy advertised. Position title change at one of the project sites.

November 1998

- Interviews for project coordinator position.

December 1998

- Renewed request to HRSA regarding project site issue (see Nov. 1997). SPNS project officer offers information and additional contact information. Project officer relays information to technical assistance office and arranges a conference call between HRSA, the site, and NNAAPC. During call, HRSA requests written materials as backup to request for assistance.

January 1999

- Continuation application submitted. Request increase in funding to support case managers at 100 percent FTE, to conduct a training for case managers and to conduct site visits.

- Site visit at two case management sites

Feb 1999

- Project site (see Nov. 1997) submitts written materials to NNAAPC, and these were forwarded to SPNS project officer. Additional information from other minority agencies requested by HRSA to substantiate claim.

- Notice of Grant Award; project objectives altered to reflect funding amount, i.e., no case manager support, training or site visits.

May 1999

- Site visits at Hawaii project sites, using year 1997 carry-over monies.

June 1999

- Site visit (see Nov. 1997), using year 1997 carry-over monies.

- New project coordinator starts working.

July 1999

- Medical student starts summer internship to enter, clean, and analyze baseline evaluation data.

August 1999

- Medical student intern submits preliminary draft report of substance abuse/HIV profile from baseline client data.

- Initiation of electronic version of client monthly report forms for subcontractors.

Oct 1999

- Move to new physical location.

December 1999

- Ongoing work on code books in conjunction with Navajo project to ensure both projects have identical data systems.

Jan 2000

- Project site (see Nov. 1997) receives notice that the city was planning to award them funding for native clients.
- Continuation application submitted. Changes requested include: part-time interviewers, full-time case managers. Change of status of the Oklahoma sites, from a NNAAPC arm to independent 501 (c) 3. The Ahalaya Native Health Care Center now functions as a subcontractor.

February 2000

- Notice of Grant Award; program objectives change to remain compatible with this funding level.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by NNAAPC, you are welcome to contact the project director and request technical assistance:

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Project Bridge: Prison and Drug Detox Program, The Miriam Hospital

Linking HIV-positive Inmates to Services after Release

Authors: Leah Holmes, Deborah Davis, Randy Sell, Len Mitnick and Robert Sember

Introduction

Project Bridge provides intensive case management and medical follow-up to HIV-positive ex-offenders. The project's primary goal is to improve medical continuity of care through social stabilization. This intervention model depends upon intensive outreach efforts and collaboration between the correctional system and project staff.

By addressing medical needs within the context of comprehensive care, including substance abuse treatment, social support and psychological help, the program can remove both logistical and psychological barriers faced by clients. Almost half the clients served are multiply diagnosed with HIV, a mental health disorder and a substance abuse disorder. The project helps clients negotiate the service delivery system and promotes teaching the clients how to assume responsibility for becoming appropriate self-advocates.

During the past three-and-a-half years, the project has learned a number of instructive lessons about how to provide consistent and comprehensive medical care, work within correctional system constraints, and provide intensive community-based and cost-effective outreach.

Location

Project Bridge targets HIV-positive ex-offenders who are still incarcerated at the point of initial contact. Because it is a small state, Rhode Island operates all of its correctional facilities on one campus, which is

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located in Cranston. There are five separate correctional facilities, an Intake Center that functions as a county jail, and one work release facility.

Project Bridge clients obtain a level of self-sufficiency and stay engaged in medical care at the rate of 80% after program termination.

Project Bridge serves men and women completing sentences from all sites of the Adult Correctional Institutions (ACI) except the Intake Center. The primary project site is in an old Victorian house in a neighborhood in the center of the city. The project director, case managers and other intervention staff have offices at this site. The medical care component is located at The Miriam Hospital, also in Providence. Project Bridge is very mobile, with case managers and case management assistants providing much of their direct services through a community based model. The case management teams see clients in the prison, on the streets, shelters, substance abuse treatment centers, neighborhood stores, individual homes, and wherever else the clients may be found.

Services

As part of the intervention, clients are enrolled and maintained in primary care. They obtain financial benefits and housing applications. They develop a therapeutic alliance with a case manager over time. They obtain a level of self-sufficiency, and stay engaged in medical care at the rate of 80 percent after program termination.

The majority of Project Bridge enrollees are referred from the prison's medical services department 30-90 days from their release date. Clients must agree to participate in all aspects of the program, including data collection. Clients also must be willing to sign consents to Project Bridge for family members or friends who will know where they can be located should they fail to keep appointments. Clients must be age 18 or older. There are no restrictions based on substance use or type of offense.

The presence of a case management team is a vital link to the establishment of stability for the newly released offender. All clients are assessed for readiness for substance abuse treatment, but maintaining sobriety is not a condition of enrollment. With respect to medical follow-up, the case manager identifies all the medications that the client is taking. By submitting an application to the state AIDS Drug Assistance Program, arrangements are made to ensure that HIV medications are obtainable after release. Psychiatric and non-HIV related medications have to be secured through other means. Clients receive a medical appointment scheduled within ten days of prison discharge. The social worker is present for the client at all medical appointments. The social work assistant generally accompanies the client to social service appointments.

Provider Team

The teams consist of a professional social worker (MSW level) and a social work paraprofessional who provide complementary skills. The process begins by contacting the potential client 30-90 days before the prison release date. An initial treatment plan is formulated using the client's identified needs and goals at the point of prison release. Together, the client and the social worker anticipate needs for temporary housing, medications, medical and psychiatric appointments and referrals for concrete services.

In addition, the program works with small numbers of case managers and assistants. The average caseload is between twenty-five to thirty clients. Although the intervention is very intensive, the program is time-limited. The model promotes teaching clients, over time, how to assume responsibility for becoming appropriate self-advocates. Through first modeling, then rehearsing and finally moving to a coaching position the social worker encourages the client's developmental progression. Program staff are intensely involved with the clients, but the program does not become saturated because of the discharging of clients as their period of program enrollment ends.

The Transition from Correctional to Care Systems

Coordinating the care of HIV-positive clients who move from prison to the community requires working across a number of markedly different systems. The mission of the correctional system is profoundly different from the mission of medical facilities which differ, in turn from the approach taken by community based social service providers. Project Bridge case managers learn how to engage effectively with these multiple systems in order to ensure a continuity of care.

Lesson #1: Develop and maintain good relations with corrections staff.

By coordinating discharge planning between the correctional setting and community-based providers, ex-offenders can be mainstreamed back to their community without an interruption in their care. In order to accomplish this, providers from the community must come into the prisons to make a personal link with the clients and secure the support of key correctional staff so as to ensure access both to the clients and critical information such as up-to-date health reports and accurate release dates. Getting into the prison system and developing constructive relationships with correctional staff is a challenging task.

Understand and respect the mission of correctional facilities

Community care providers and correctional staff have different priorities. Correctional facilities have a primary mission of protecting visitors, staff and inmates from violence. Care providers are concerned with the health status and quality of life of individuals. Conflict between these priorities should be avoided. There is room for common ground and this should be sought out by the community provider and expressed in a manner that is respectful of the protocols of the correctional facility.

Safety is the priority in prison settings

Correctional officers judge their effectiveness in terms of maintaining a secure unit. They accomplish this within a highly controlled system that leaves little room for flexibility. Officers are also confronted daily by hostile, negative situations that can breed discontent for all involved. The nature of the prison system is such that correctional staff seldom have the opportunity to interact with former inmates who leave the facility and make significant positive changes in their lives. They are more likely to encounter inmates who are reincarcerated. This characteristic of the prison setting challenges the convictions of even those correctional staff who see their function as rehabilitation. Whatever the view of the correctional staff, safety is the priority. To apply the social work value of client self-determination within a correctional setting may not be valid or safe and may well result in a direct conflicts with prison policies.

Maintain the distinction between prison setting and program staff

Project Bridge staff work collaboratively with the corrections system and have sustained positive and

Cost Savings

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The cost, per client, for 18 months of Project Bridge Services:

w/o a mental diagnosis
$5,446.05

with a mental diagnosis
$8,396.59

The cost, per inmate, for 12 months in a correctional facility:
$40,000.00

constructive relationships with key correctional staff over the life of the project. The key to maintaining these relationships is following corrections protocol. Yet, Project Bridge staff ensure that they do not become identified with the correctional setting. Their mission, to support inmates following their release in an environment that is significantly different from the one maintained within the prison, is clearly communicated to clients. The core relationship with the client is the one that exists once the client has left the correctional setting. In order to reduce the possibility of having the relationship closely identified with the prison setting, case managers do not engage in the discharge planning process too early.

Lesson #2: Establish continuity of care across settings.

Several clients have reported never receiving any type of health care outside the correctional system while others have had trouble negotiating the system in the past and fear re-engaging with providers in the community. Receiving services from the same community based medical and case management providers both in the prison and in the community breaks the artificial division of the two worlds and allows for continuity of care.

Barriers to care

The barriers to care are both institutional and personal. Institutional barriers include delays in obtaining appointments, attitudes and behavior of medical staff whose professional demeanor is perceived as uncaring or judgmental, lack of health insurance and or money for the co-payment, need to identify a primary care provider for a managed care plan, or difficulty reaching the treatment location because of lack of transportation. To these institutional barriers are added those of the client which include, anticipation of rejection, active substance abuse, fear of medical procedures, distrust of medical providers and a desire to deny the reality of being HIV positive.

Anticipating release

These barriers can be overcome. Having an identified person to assist with the basic needs at the point of prison release provides a lifeline. Case managers must prepare for the difficulties of release in the weeks leading up to the discharge date and must plan the first meeting in the community. Anticipation of the release dates heightens anxiety which in many instances triggers cravings and urges related to drug use. When appropriate, this tension is addressed directly by the social worker with the client before release.

Assisting at the point of release

Clients are particularly vulnerable in the 24 hours following release and it is most effective if the case management process that began in the prison continue immediately after release. The focus of the first case management session following release must be on reducing the client's anxiety and ambivalence. If unchecked, fear and guilt can undermine an individual's willingness to engage in care.

Meet in client's home or neighborhood

Relapse into substance abuse and high-risk behaviors is the greatest contributing factor to loosing a client to follow-up. Ex-offenders are faced with enormous stress during this time. More often than not, individuals return to the same geographic area where their arrest occurred. Their social contacts in that location revolve around drug use, and associated illicit behaviors. It is critical for the case management team to make contact with the client within the first week after release to avoid or mitigate relapse. The post-release appointment is made in the client's home or neighborhood.

Continuity of medical care

Project Bridge case managers and physicians from The Miriam Hospital establish a continuity between the medical care received in the prison and that accessed in the community. The physicians who see the client after release are the same physicians who treated the client throughout his or her prison stay. This leads to a better understanding of the individual's specific needs and reduces the anxiety of the clients. In addition, case management staff assist clients in making medical appointments and provide transportation by either taxi or bus. In meeting the goal of maintaining clients in primary care, case managers have discovered it is very important to accompany clients on their clinic visits to ensure that clients ask providers questions concerning care. The case managers frequently supply pertinent information. They also ensure continuation of HIV medication through submitting ADAP applications prior to the client's prison release.

Case Management

Outreach is critical to the success of the program. Client encounters occur on the streets, in shelters, in substance abuse treatment centers, during both psychiatric and medical hospitalizations, at neighborhood stores, in clients' homes, and in the prison should a client be reincarcerated. In order to conduct effective outreach and build on the access it enables, Project Bridge relies and the skills of a diverse team of case managers and case management assistants who work collaboratively to address the needs of each of the program's clients.

Lesson # 3: Employ a team approach.

The case management component of the project uses the skills of master level social workers as case managers and peer workers or members of the client community as case management assistants. This model respects the complementary skills and abilities of both professional training and natural helpers.

The clients learn to use the team members differently

When approaching a service or situation that causes heightened anxiety, clients want the presence of the case manager who is able to address issues within the care system and help the clients process their emotional and psychological experiences. Case managers provide overall treatment planning, strategic behavioral interventions and client advocacy. They also support the client management assistants in identifying and maintaining appropriate interpersonal boundaries.

When clients are dealing with familiar situations they are more likely to choose to work with case management assistants. Because of their personal histories the case management assistants develop important supportive relationships with program enrollees. They provide much of the support that does not require the skills of a master's level clinician, such as accompanying people to appointments, finding people on the streets and providing concrete support for recovery from addiction.

Through the team approach "burn-out" is minimized as no one person is encouraged to feel individually responsible for the clients.

Minimizing staff turn-over

Staff turn-over is expensive and disruptive to clients who are emotionally fragile and have difficulty coping with what they are likely to perceive as another episode of abandonment. Through the team approach, worker burn-out is minimized as no staff member is required to be singularly responsible for a client. The staff work collectively to meet the diverse needs of a complex population of clients. Regular communication through case conferences and supervision meetings with the project director minimizes stress, increases skills and maintains effective professional partnerships. Staff are encouraged to represent the project in professional meetings which increases a sense of joint ownership of the project.

Lesson #4: Locate the community case management office.

In January 1997, the Project Bridge office moved from The Miriam Hospital to a facility within the community where the majority of clients live. This move greatly facilitated client contact in two ways. First, it reduced the distances staff travel to meet with their clients. Second, it provided the clients with a setting that is not identified in any way with HIV care. Clients stop in to meet with team members, to attend a group, or to complete evaluation questionnaires. Those who do not have a reliable address collect their mail at the office.

Working with Ex-offenders

Most program clients find it very difficult to negotiate the service delivery system. The barriers are both logistical and psychological. Helping clients identify and resolve these barriers is one of the central tasks of Project Bridge staff. Staff focus on resolving intrapersonal issues and building the skills needed to survive health and social services settings. The goal is to help clients gain self-sufficiency.

Lesson #5: Take the clients as they are.
Since many prisoners experience their first incarceration early in life, they seldom have the opportunities to learn the basic skill required for adult life. Many of the social and institutional skills taken for granted by the community are foreign to ex-offenders. The survival skills they were able to develop, such as dealing drugs to make money or using drugs to subdue emotional trauma, are often high risk and lead to infection and incarceration.

Building skills for living
The time individuals spend in prison re-enforces a sense of victimization and learned helplessness. Inmates have little choice in the most basic areas of living, such as when to eat, sleep, or recreate. For many who have had multiple incarcerations, prison is their home. Upon release to the community they are confronted by responsibilities they have little ability to meet. To build or restore these everyday functioning skills, takes time, patience and careful, non-judgmental guidance.

Harm reduction
Building the trust required to help clients develop the skills and confidence to live in the community is the first step. In order to facilitate this trust while providing access to necessary medical services and minimizing risk, Project Bridge follows a harm reduction approach. Program participation is not conditional upon the acceptance of treatment for either substance abuse or mental health problems. However, if a client threatens suicide, aggressive action is taken.

Engaging in care
The first four years of program activity has show that ex-offenders do care about their HIV status and will remain actively involved in health care when given adequate and non-judgmental support. Following a harm reduction model does not mean that program staff do not address substance abuse issues. From the beginning of the case management process, clients substance abuse treatment plans are explored to identify the client's choice (i.e. methadone maintenance, 12-step programs, or residential treatment).

> The large number of clients that have remained in the program shows that when given a viable choice, even the most disadvantaged members of society will seek to participate in a program.

Client retention
The harm reduction model is an essential component in client participation and retention. The program completion rate is very high; 86 percent of the clients have remained in the program. In fact, fewer than three percent of clients have been lost to follow-up. The fact that such a large percentage of clients have remained in the program highlights the fact that when given a viable choice, even the most disadvantaged members of society will seek to participate in a program that provides continued care.

Lesson #6: Trauma related mental health needs are high.
Clients are assessed for both mental health and substance abuse treatment needs. The psychological health of the individual becomes part of the care plan. Mental health issues such as anxiety disorders, affective disorders, schizophrenia and personality disorders are common and are likely the foundation for the high level of self medication through drug use.

Early trauma is a common experience
A history of emotional, physical, sexual abuse or other trauma is reported by 78 percent of the program participants. Many clients describe growing up in environments where violence was commonplace. These childhood experiences make it difficult to imagine any other way of resolving conflict. In dysfunctional homes, accepting responsibility may result in abuse. Parents who are addicts may look for someone to blame instead of problem resolution. Because the world is unsafe, the clients experience themselves as victims and

not as creators of their circumstances. Victimization is an everyday occurrence. Accepting responsibility for actions may mean accepting a sense of profound shame. Overcoming this shame is a life long process. The case managers try to initiate this work during counseling and group sessions.

Mental health needs increase costs

The cost to provide Project Bridge's services to a client with a mental health diagnosis is greater than to a client without such a diagnosis. When Project Bridge reviewed the total cost per client for case management and outpatient care for those clients who had been deactivated, they found that there was a difference between the groups. The cost was based upon case management and outpatient services only and does not reflect the additional cost of hospitalization and emergency department care. The mean cost was found to be $8,3966.59 for those with and $5,446.05 for those without a mental diagnosis. This finding could have important implications for funding sources in planning for resource allocation. This cost is for an 18-month enrollment period and compares very favorably to an annual cost of $40,000 for a prisoner to be housing in the Rhode Island correctional system.

Lesson #7: Advocate for clients.

Combating distrust and stigma

Experience teaches clients to anticipate negative reactions from providers. Service providers confirm this expectation by rarely extending themselves on behalf of ex-offenders who are viewed as resistant and unreliable. Clients test providers to see both how gullible and how reliable they are. If providers are gullible, clients won't respect them.

Mutual distrust leads the clients to think that return appointments are a subtle form of rejection while lack of appointment keeping by ex-offenders is seen by the provider as further evidence of the client's lack of motivation. To break this cycle, case managers have to advocate for both clients and providers, educating both about the beliefs and expectations of the other. If providers are reliable over an extended period of time and clients engage meaningfully with care, trust will develop.

From clients to case managers

To increase client's trust in and ability to work with the service delivery systems, Project Bridge staff model various behaviors for the clients and over time encourage them to advocate for themselves and assume increasing responsibility for their case management. For example, when clients are denied services, they are assisted in requesting and completing an appeals process. Without the modeling, support and provision of resources, most clients would never consider appealing a denial of service. This process has had an impact on the procedure followed when clients approach the end of their 18 months with the project. At about month 15 clients are triaged. Staff have found that some clients can be their own case managers, while others are transferred to other programs.

Project Bridge Chronology

October-December 1996

- Meet with representatives of potential collaborative agencies to outline the intervention and execute memorandums of agreement (9 agencies).
- Create job descriptions and open positions for hiring.
- Draft versions of forms for the intervention.
- Interview candidates for key staff positions.

January-March 1997

- Begin development of database to track intervention and demographics.
- Hire one case manager, one outreach worker and secretary.
- Begin program enrollment.

- Case manager meet with staff of collaborating agencies to explain program and clarify ways in which Project Bridge's mission complimented theirs. (20 programs receive this intervention.)

- Create referral protocol with staff at the prison by having the case manager attend weekly HIV specialty clinic.

- Case manager and outreach worker receive training at the prison on protocols and receive visitor badges.

- Submit material to the Institutional Review Board (IRB) for approval.

- Develop brochure to distribute to social service staff at the prison.

April-June 1997

- Move the office to a facility within the community where the majority of clients live.

- Begin weekly half-day clinic for program participants at the community site, which is an enhancement to the HIV clinics at the hospital's outpatient facility.

- Initial case conferences held for program participants.

- Additional staff hired and trained. Staff: 1.5 FTE case managers, 1 FTE outreach worker, 1 FTE secretary.

July-September 1997

- Second .5 FTE case manager begins duties.

- Begin program dissemination activities.

- Site visit by ETAC and project officer.

- Further refinements to program forms to track case conferences and semi-annual reviews.

October-December 1997

- Search for a larger facility as the size of the program and the weekly clinic determined the need.

- Initiate plans to create a comparison group for evaluation purposes.

- Create a client satisfaction survey methodology.

- Purchased additional necessary office equipment (fax, shredder and copier).

- Principal investigator takes a sabbatical from the hospital.

- New principal investigator hired.

- Second case manager expands from .5 FTE to 1 FTE and second outreach worker position opened for recruitment.

- Staff attend data training at ETAC.

January-March 1998

- Move to new location, program director now on-site.

- Expand database needed to accommodate multi-site evaluation elements.

- Revised forms to accommodate multi-site evaluation.

- New principal investigator begins providing care.

- Final version of multi-site evaluation revisions implemented.

- Second outreach worker hired.

- Chapter for book for correctional health care workers written.

April-June 1998

- Evaluator leaves for new position.

- Search for new evaluator begins.
- Second outreach worker dismissed.
- Dissemination on-going.
- Further refinements to forms to include termination summaries.

July-September 1998

- Begin recruitment for replacement outreach worker.
- Secretary resigns.
- Evaluator hired on contract basis.
- Recruitment for replacement secretary begins.
- Begin terminations for clients who have completed the program.

October-December 1998

- Research assistant hired as 5 FTE.
- Secretary and outreach worker hired.
- Article published in *Journal of Correctional Health Care.*
- Principal investigator leaves the hospital for another position.

January-March 1999

- First outreach worker is recruited by local Title IV program.
- Recruitment begins for replacement for outreach worker.
- Difficulty in converting medical database information into acceptable format delays data submission.
- Invitations to disseminate proffered.
- Preliminary planning for a regional meeting with other PSC members who offer mental health services within a medical setting.
- Request to IRB for change to protocol concerning the comparison group and implementing focus groups for evaluation.

Further Information and Technical Assistance

Should you wish to obtain additional information about Project Bridge or the service delivery model, you are welcome to contact the project director and request technical assistance:

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Reaching Border Migrant and Seasonal Farmworkers

Authors: Terence Doran, Lucia Bustamante, Sandra N. Duggan, Dale Schweers and Maria Caban

This article chronicles some of the lessons learned from La Frontera Project, a SPNS-funded program developed by the University of Texas Health Science Center at San Antonio, Texas. The information is based on interim findings from the first three-and-a half years of a five-year demonstration project. Final results of the evaluation will be available upon completion of the grant cycle in Fall 2001.

Introduction

Texas is home to the second largest population of migrant and seasonal farmworkers (MSFW) in the United States. The predominately Mexican-American MSFWs in south Texas are among the most impoverished, medically underserved populations in the US. Access to health care is impeded by chronic seasonal unemployment, high poverty rates, low educational levels, substandard housing, lack of health insurance, transportation systems and seasonal work-related migration. Despite the presence of conditions that often accompany HIV, there are few data available regarding the prevalence of HIV/AIDS for this population.

The La Frontera model was designed to address special challenges posed by a mobile population with characteristics that place its members at risk for HIV as well as other infectious and chronic diseases. The project provides an innovative approach to service delivery through the development of formal partnerships to link and integrate the services necessary to meet the special needs of the HIV-positive MSFW population.

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La Frontera is a collaborative partnership headed by the University of Texas Health Science Center at San Antonio, Department of Pediatrics, Division of Community Pediatrics. The project was conceived in response to a lack of information about the rate of infection among MSFW residing along the Texas-Mexico border, specifically in Hidalgo and Maverick counties. Project La Frontera is a collaborative partnership of HIV service delivery and migrant service organizations with extensive experience and skills in delivering care and services to people living with HIV and populations of MSFW and their families in the target area.

Historically, the two service delivery systems of HIV care and migrant care had never worked together to deliver services to HIV-positive MSFWs living in south Texas. Thus, an innovative feature of La Frontera is the development of linkages between these delivery systems to coordinate a continuum of accessible HIV care and support services for MSFW families at their home base and as they migrate for work. The ultimate aim of La Frontera is to enhance and link existing systems of care into a coordinated delivery system of HIV care and services tailored to the unique needs of MSFW and their families at their home base, during migration and at their destination site. These linkages will remain and continue to provide a continuum of care well beyond the SPNS funding cycle.

Location

The name “La Frontera” was selected to reflect the unique geographic and cultural characteristics of the population to be served. The project’s partner agencies provide medical and psychosocial services to MSFW residing in south Texas. For migrants away from south Texas, housing is typically temporary and substandard with inadequate water, electricity and sewage. At their permanent winter base along the south Texas border, many families cannot afford traditional housing and must often live in communities referred to as “colonias.” Colonias are typically found in unincorporated areas outside of the city limits and are not subject to zoning regulations. Homes are frequently near the Rio Grande River where ground water is three to four feet below the surface. This makes the septic systems nearly useless, since drainage is often poor and flooding is common. In addition to the severe poverty typical in these neighborhoods, colonias are physically isolated from mainstream society and the majority of streets are unpaved.

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What is a colonia?

Unincorporated, rural settlements along the Texas/Mexico border

- Substandard housing
- Inadequate water and sewage services
- Limited basic services
- High unemployment rates
- Low per capita income
- High incidence of disease
- Low levels of educational attainment
- Speak predominantly Spanish
- In 1994 there were 1,436 colonias with more than 340,000 residents

Services

In a survey of 60 farmworker service program representatives, major gaps were found in HIV-related services. Until recently, services had been developed without careful consideration of the population to be served. Lack of knowledge about this population’s HIV medical and psychosocial needs necessitated the development of an integrated service delivery model. The model is designed to develop formal partnerships among health and human service organizations specializing in the field of HIV/AIDS and migrant service delivery providers.

La Frontera’s target population is comprised of HIV-positive MSFWs and their families residing in Maverick and Hidalgo counties. The project has developed and implemented an innovative outreach strategy targeting residents of colonias. Trained lay health workers (consejeras and promotoras) from the community serve as HIV educators. The focus is on culturally appropriate education, pre- and post-test counseling, HIV testing and referrals to appropriate resources in the community. Prevention information is in the context of the data collected through the SPNS multi-site evaluation collaboration.

In addition, a significant part of project work was to explore health care utilization patterns and individual and system level barriers to health care. The project aim was to establish continuity of care for MSFWs by linking existing health and human service delivery systems that provide comprehensive HIV-related care and services to the target population both at home base and while migrating. Finally, the protocols of care for HIV infection in MSFWs and the integrated service delivery model developed by La Frontera can be replicated to address other chronic illnesses in mobile populations.

Provider Team

The University of Texas Health Science Center at San Antonio, Division of Community Pediatrics functions as the lead agency in the La Frontera partnership. The La Frontera Partnership consists of the Valley AIDS Council (VAC), the United Medical Centers (UMC), the National Centers for Farmworkers Health (NCFH), and the Migrant Health Promotion (MHP). Three of the collaborating partners are lead agencies for the provision of services to MSFWs and are a part of established networks in the delivery of culturally competent health and human services for the target population. Two agencies have been influential organizations in the development and delivery of HIV/AIDS services in the project areas since an HIV-focused delivery system began emerging in south Texas during the 1980s.

Through the partnership, agency representatives share experiences about the service provision and referral network. Each agency also receives up-to-date information regarding HIV/AIDS and migrant issues that are particular to their agency and service area, technical assistance on data collection and evaluation activities, grant writing and assistance in using La Frontera data to support the need for additional funds. Partners also participate in the compilation and dissemination of findings.

Lessons Learned

Lesson #1: Account for regional culture and structure.

In order to estimate the seroprevalence of HIV among migrant and seasonal farm workers in South Texas, the colonias were mapped and an outreach survey was conducted in the colonias of Hidalgo and Maverick counties. Since existing maps were outdated, the colonias had to be remapped in order to undertake this count.

The literature is inundated with information regarding the vast amounts of unmet medical and psychosocial service needs in hard-to-reach populations, however, there is very little or no guidance on how to provide services to such clientele. The work conducted by La Frontera would not have been possible if the project did not have a good estimate of the migrant population in the area, the proportion of migrant households in the colonias to non-migrant households, and the specific location of homes. The mapping of the colonias, although time consuming and costly, was crucial in the identification of the population and the provision of services.

Promotoras

During the pilot testing of questionnaires La Frontera project learned from the promotoras that migrant workers expressed concerns about confidentiality, and were not willing to provide personal tracking information. La Frontera employed promotoras/lay health workers from the community to provide HIV education, conduct the outreach survey, offer HIV testing, offer pre- and post-test counseling and referrals to appropriate agencies as necessary. The promotoras were migrants themselves and were trusted by the community. La Frontera project provided the training of the promotoras and in turn gained the trust of the MSFWs. This reflects the importance of taking into account the clients' culture and concerns.

Language

The promotoras also assisted the project in the revisions of the questionnaires. La Frontera did not anticipate this key role that the promotoras played. The promotoras recommended that in addition to making the materials available in Spanish, culturally appropriate terminology and phrases needed to be incorporated in the questionnaires. The instruments were targeted specifically for the MSFWs population in Texas.

Questionnaires and other related materials were made available in Spanish, the language primarily used by the MSFW population. The promotoras administered questionnaires in Spanish and services were also available among the partner agencies in Spanish. Programs need to allocate resources to the translation of instruments, employ personnel who speak the language and know the culture, and take into account its effect on the data findings during the evaluation process.

During the qualitative interviews, one client summarized the need for the availability of HIV/AIDS literature in Spanish as follows:

> “*Yo pienso que deberían de ser más publicada con los migrantes allá porque cuando yo está no había nada de eso, así que dijeran del SIDA. Y que hagan más cosas en español porque hay muchos que no saben inglés y si pasan todo en inglés no van a sabér.*
>
> *I think that [information in upstream] should be published more geared towards migrants because when I was up there, there was nothing of that, that would speak about AIDS. And that there should be more things in Spanish because there are many who do not know English and if there's only information in English, they are not going to know.*”

Customs and spirituality
The relationship with God is an integral component in the lives of the MSFW population affected with HIV/AIDS. Clients report a strong sense of faith as they live with the disease. Some involve themselves in prayer, others in participation in formal churches and others to the cultural folk healers (curanderos). Their outlook on life has changed from negative to positive as a result of their faith:

> “*...So as long as he [God] keeps me healthy and going,*
> *I will be trying to help other people.*
>
> *...Por la fé mia, vereda que el Señor me a sanado, pos me ha hecho sentír bién.*
> *...Because of my faith, proof that the Lord has healed me, it made me feel better.*”

Many physicians report an understanding of the role that religion/spirituality plays in the lives of clients and are accepting of it as long as it is in conjunction with the medical aspect of their care.

Lesson #2: It's important to acknowledge existing care-seeking practices
As a result of formal interviews and informal exchanges over the years of working with migrant communities, we learned that basic knowledge about HIV disease is absent. The belief expressed by one HIV-positive client that, "AIDS is like you die real quick," was common and has a significant impact on how infected individuals seek care.

The fear of confronting the inevitable consequences of being infected accounts in part for the low rates of HIV testing in these communities. The result is that most migrants are identified late in the progression of the disease. The decision to seek care is one that is taken in the context of the migrants' working and family lives and when the consequences for others is considered the fear only increases.

When contemplating their HIV illness, women describe thinking immediately of the welfare of their children and they are convinced that they will loose their children if their status is discovered. Workers, always burdened with employment instability, fear the loss of their jobs and their inability to meet family obligations. And the economic impact for those who develop AIDS is very real. As one provider noted: "Due to the debilitating effects of the disease and medications and the harshness of the type of work, most of the migrants we interviewed have stopped migrating."

With a strong work ethic that is generations deep, the loss of employment has an impact that extends beyond concerns about economic stability. As one client on public assistance notes: "I feel kind of idle and bored because I feel now that I can do something (but) I know that if I go and get a job of any kind, they will cancel my medications, which I can't afford on my own. They are $1,400 a month." It is important that providers acknowledge and assist clients deal with the feelings of frustration and worthlessness that result from their inability to work.

Alternative health care

While migrants may have difficulty or resist entering the mainstream care system, alternate or tradition health care providers may be more easily accessed and approached. Belief in faith healers (curanderos), is very strong and an important component of the community law on how to deal with AIDS. Events like the one described here are extremely influential at both an individual and community level.

One client interviewed by La Frontera workers described a time when she was extremely ill, had been hospitalized and suffered extensive weight loss. She was taken to see a curandero:

> “ *[I was] 97 pounds! I was in the hospital so I had to sign release forms so they could take me. It's up on the hill. There is no water, no electricity, nothing! He just gave me . . . well, herbs to purify/cleanse my blood in a tea. He also gave me energy with his hands. And he prayed. After two days on the hill, I began to feed myself...* ”

The power of these experiences was enhanced when the client later visited her physician whom she quotes as saying:

> “ *It's just that you had 3,300 copies of the virus and now you only have 300; and your CD4 count was 20 and now it is 150. It is too soon for this to be a response to the new medications I put you on; I don't think they could have helped you so quickly.* ”

The physician ordered a second round of tests to confirm these counts.

By sharing this story with providers and others in the community the client made it clear that she is willing to seek conventional HIV care but has a strong belief in the curative effects of the curandero. Both systems of care have to work together and for communities such as these the integration of care systems must also account for the existence of alternate care systems and care seeking patterns.

Lesson #3: Maintaining linkages is crucial.

In establishing linkages and/or networks, agencies have to know about each other and be clear about the role they will play when partnering. It was important to keep in mind that each agency is different, with its own history and method of providing services to the same population. This, of course, takes time and the work of many of the agencies' staff. The work does not end once the linkage/relationship is established.

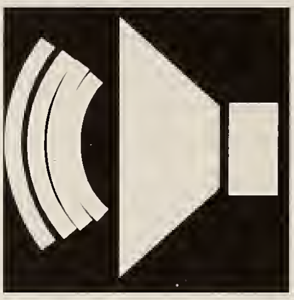
Partner roles, responsibilities and contributions to the project may change over time due to project findings and nature of work to be completed for successful completion and attainment of goals and objectives. Furthermore, it is critical to maintain flexibility in working relationships because there are limited or no other choices for working with different agencies.

> ...agencies have to ... be clear about the role they will play in the partnership. The fact that each agency is different with its own history and method of providing services must be respected.

La Frontera learned that many agencies participate in the partnership because they receive additional resources in the form of personnel or money. Partner agencies should anticipate and discuss possible decreases or cuts in the allocation of project funding. La Frontera experienced difficulty in the continuing collaboration of one partner agency when there was a decrease in funding. This requires preparation from both the leading agency and the participating agencies. There should be common goals with the expectation that they may change over time.

Information collection
Information gained from La Frontera is used to inform HIV service agencies, migrant health delivery systems as well as health and human service providers at the community, regional, state and national levels about the needs of migrants, risk factors, level of HIV awareness and lack of HIV knowledge. The agencies are benefiting from the availability of migrant information such as availability of life insurance, medical history, and service utilization. Agencies are becoming more aware of the need for the continuum of care.

A multilevel evaluation design was used to document the implementation, the collaborative process and to track progress of project activities, primarily baseline data, training activities, and aspects of the delivery system such as quality, accessibility and continuum of care of HIV patients as they migrate.



Communication is key to maintaining linkage

Collecting data
Using project-specific software
Training
Multi-level evaluation
Information sharing

Training staff on research and evaluation
To guarantee the contribution of data, partners were provided the following services and training: installation of project software, development of databases, computer training, explanation of the necessity and usefulness of project data, procedures for the systematic collection of data, data entry, quality assurance techniques, data analysis, and summary of data. Partners also received training on interview processes and techniques, HIV education and migrant related issues, the needs and characteristics of the target population, research methods, grant writing, and searching for funding opportunities.

Availability and sharing of preliminary findings
In collecting data, staff learned the importance of evaluation as a means of showing the effectiveness of the project. Staff and partner agencies were given preliminary findings of the client data on a periodic basis. Sharing the findings of the study encouraged the continual collaboration and motivation for further data collection. Multi-site data collaboration enhanced the availability of data on the MSFW. La Frontera is in a position that allows for demographic data and preliminary findings to be available to agencies and the state on a regular basis. However, information on migrants' experiences was not being captured. The project agreed to enhance the quantitative data by the inclusion of qualitative data.

La Frontera is collecting qualitative data via case histories. The case histories capture detailed information on the following: (1) what is the hardest thing to deal with in living with HIV/AIDS; (2) knowledge of HIV/AIDS; (3) health care upstream; (4) health care in Texas; (5) how HIV affects migrant work; and (6) spirituality. Due to the frequent mobility and migration patterns of the target population, it was difficult to conduct follow up interviews and assessments. Often times, clients had left the region, died, or did not have a telephone and/or transportation.

La Frontera Project depends on agencies' cooperation to get client personal identification information. Many clients did not feel comfortable completing tracking information for the project but were accepting of giving the information directly to the agencies. The agencies in turn made the information available to La Frontera. Funding and resources greatly affect the level of cooperation among the partnership.

Information sharing
Dissemination activities include presentations at workshops and conferences and the publication of scholarly articles. Moreover, information regarding lessons learned and information gained from La Frontera are developed for a variety of audiences through a variety of venues. A website was developed and is systematically updated to reflect project activities. It also includes results from the seroprevalence study, information on the partner agencies and links to other related websites. Data is summarized and reports generated to document the needs of service providers and populations. As a result of the findings, the Department of Health has incorporated the migration status question in its reports. The goal is for agencies to sustain a regional collaborative of keeping demographic data on intake form at the completion of the project.

Agency quarterly reports, partnership meetings, conference calls and e-mails
Partner agencies submit quarterly reports. Reports contain documentation of agency newsletters, periodicals, joint presentations, staff training events and funding opportunities. Correspondence through the development of e-groups was set up for La Frontera. The purpose of these groups was to allow members to communicate either by e-mail, or in real time through on-line conferences at no cost to the individual members or the partnership. The only requirement was Internet access. This technology has allowed for efficient communication between members and dissemination of documents without the expense of fax, mail or courier. Perhaps the greatest benefit has been the group's exposure to the benefits of this advanced technology.

Newsletters
La Frontera newsletter contains project research study findings and HIV/AIDS information that is systematically updated and distributed at local and regional conferences. La Frontera articles discuss methods of increasing awareness of HIV disease in migrant populations, HIV risk factors in general and risk factors that are unique to the MSFW population.

La Frontera Project Chronology

October 1996

- Staff selection.
- Develop project timeline (ongoing reviews throughout project).
- Conference calls to initiate development of outreach screening instrument.
- Initial site visits to assess colonias in Hidalgo and Maverick counties.
- Develop baseline agency linkage table.

November 1996

- Finalize contracts with partner agencies.
- First La Frontera partnership meeting convened.

December 1996

- Develop migrant outreach screening instruments (English and Spanish).
- Initiate development of quality assurance instrument for outreach screening instrument.
- Initiate development of quality assurance procedures for outreach field activities.
- Develop database to monitor dissemination activities.

January 1997

- Memorandum of understanding signed by all partners.
- Pilot test outreach screening instrument with promotoras.

February 1997

- Field test outreach screening instrument in Hidalgo and Maverick counties.

- Meet with community and organizational leaders in Maverick County.
- Develop timeline and review specific tasks.

March 1997

- Develop baseline profile of health providers and social services available to MSFWs in Hidalgo and Maverick counties.
- Develop baseline profile of HIV health providers and social services in Hidalgo and Maverick counties.

April 1997

- Meet with community and organizational leaders in Hidalgo County.

August 1997

- Translation of consent forms into Spanish.
- Scouting trip to the Hidalgo county colonias.

September 1997

- Develop methodology for colonia mapping.

October 1997

- Field test outreach screening instrument in Maverick county.
- Initiate qualitative interviews with HIV-positive migrants – target 16 interviews.
- Initiated mapping of colonias in Hidalgo and Maverick counties.

November 1997

- Develop and train outreach staff in mapping of colonias.
- Train outreach staff on outreach screening instrument and in survey methodology.

December 1997

- Field test and final approval of outreach screening instrument.
- Develop HIV testing referral form.
- Develop instrument for reporting and tracking HIV referrals and testing activities.
- Train outreach staff on Outreach Screening Instrument, survey methodology, HIV referral/testing reporting instruments and mapping colonias.
- Initiate development of outreach activity protocols and scripts for the administration of the outreach screening instrument.
- Develop database for outreach field activities and HIV referral and testing.
- Develop qualitative interview instrument.
- Staff training on implementation of qualitative interview instrument.
- Initiate qualitative interviews with HIV-positive migrants.

January 1998

- Final approval of quality assurance for outreach screening instrument.
- Final approval of quality assurance procedures for outreach field activities.
- Implementation of discovery phase (phase 1) surveying activities; identify migrant households, offer HIV testing and provide HIV education.

February 1998

- Train outreach staff on final outreach screening instrument and in survey methodology and HIV referral/ testing reporting instruments.
- Conduct outreach screening instrument door-to-door activities to identify MSFWs in Maverick county.
- Meet with other community organizations involved in colonia outreach.

March 1998

- Initial submission of updated colonia maps to the Office of the Texas Attorney General.

April 1998

- Pilot test in-depth interview schedule in Spanish.
- End of conducting qualitative interviews with HIV-positive migrants.

June 1998

- Initial development of in-depth interview schedule (local and national).
- Maverick County finishes phase I outreach activities – 416 migrant households
- Mapping of colonials in Maverick and Hidalgo counties for seroprevalence (Phase II) surveying activities.

July 1998

- Revise consent forms to include individuals living in rural/border communities.
- Complete qualitative interviews analysis.

August 1998

- Pilot test in-depth interview schedule in English.
- Modify outreach screening instrument for seroprevalence study (phase II).

September 1998

- Develop protocols for In-depth interview schedule.
- In-depth interview schedule translated into Spanish by consultant.
- Complete mapping colonias for phase II surveying activities.

October 1998

- Final draft of in-depth interview schedule (local and national).
- Start seroprevalence (phase II) surveying activities in Hidalgo and Maverick counties.
- Pilot test in-depth interview schedule in Spanish.

November 1998

- Revise Spanish in-depth interview schedule in colloquial terms.
- Submission of updated colonias maps to Office of the Texas Attorney General.

December 1998

- Approval of outreach activity protocols and scripts for the administration of the outreach screening Instrument
- Train outreach staff on outreach screening instrument, survey methodology,

January 1999

- Modify evaluation methodology for phase II based on preliminary findings.

- Initiate effort to identify and recruit HIV-positive migrants for tracking of health access and services while migrating.
- Develop migrant tracking journal plan and data collection forms.
- Migrant status is now a requirement in the Texas HIV test reporting forms as a result of partner agency involvement in La Frontera.

February 1999

- Follow-up training to outreach staff on modified outreach screening instrument in Hidalgo and Maverick counties.

March 1999

- Approve agency assessment questionnaire.
- Completed agency assessment procedures.
- Initiate historical agency assessment with partner agencies.

April 1999

- Conclude historical agency assessment with partner agencies.
- Initiate inquiry into models for continuity of care.
- Developed database for agency linkage assessment.

May 1999

- Translated migrant journal tracking data form into Spanish.

June 1999

- Recruit HIV-positive migrants to document how they access health care and services while migrating.
- Initiate life history case studies with HIV-positive migrants or rural/border residents.
- Initiated consultant negotiation for continuity of care model.
- Article for Farmworker News submitted.

July 1999

- Field test migrant tracking journal.

August 1999

- Developed and got approval of the health provider survey.
- Developed health provider survey timeline.
- Developed health provider survey procedures.

September 1999

- Completed seroprevalence survey.
- Initiated health provider survey.

October 1999

- HIV/AIDS information for farmworkers article in the Farmworker News.
- Restructured partnership.
- Developed procedures for the agency assessment follow-up interview.

November 1999

- Completed pilot test of migrant tracking journal.

December 1999

Completed originally proposed number of in-depth interviews – continue collecting data to build data set.

January 2000

- Completed health provider survey activity at conferences.
- Developed data base for health provider survey.

February 2000

- Initiate telephonic health provider survey activity.
- Initiated case histories analysis using ethnograph.
- Initiated agency assessment follow-up interviews.

March 2000

- Initiated the process of signifying HIV services in the Midwestern stream care provider directory, La Guia.
- Completed network builder case history.
- Initiated qualitative analysis of life histories.
- Modified migrant tracking documentation process.
- Initiated in-depth follow-up interviews in Hidalgo county.

April 2000

- Initiated telephonic health provider survey activity.

May 2000

- Developed health provider database.
- Initiated in-depth follow-up interviews in Maverick County.
- Completed agency assessment follow-up interviews.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by La Frontera, you are welcome to contact the project director and request technical assistance:

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The Bridges Project, Asian and Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA)

Training Providers to Improve Service Delivery to Asians and Pacific Islanders

Authors: John J. Chin, Ezer Kang, John M. Martinez, Jen Haejin Kim and Daniel P. Schluter

The information presented is based on data available from the first three years of the program's five-year SPNS-funded demonstration grant. Reports on further progress and final program evaluation will be available in Fall 2001.

Introduction

Inadequate access and inconsistent utilization of care among Asians and Pacific Islanders (A&PIs) living with HIV-related illness have been focal concerns in New York City, where this population constitutes the fastest growing racial group. As of September 1999 there were 761 cumulative adult A&PI AIDS cases in NYC, accounting for approximately 95 percent of cumulative A&PI AIDS cases in the state and 13 percent of cumulative A&PI AIDS cases in the U.S. We estimate conservatively that at least 1,600 A&PIs are living with AIDS or HIV infection in New York City. Recent studies indicate that reported AIDS diagnoses may not accurately reflect the escalating HIV/AIDS problem within this community. Despite their growing presence and emerging HIV problem, Asians and Pacific Islanders have difficulty accessing HIV-related services. Cultural values, beliefs, and experiences coupled with a fragmented and daunting service delivery system make it difficult to access culturally competent and language-appropriate services. Moreover, for those who encounter linguistic barriers, navigating through systems of care constitutes a significant stressor. The result is that Asians and Pacific Islanders with AIDS show the highest rate of delayed care of all race groups in New York City.

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To address these concerns, the Bridges Project was developed to improve access to care by:

- integrating a range of HIV medical and social services through a system of formal linkages with comprehensive service sites and a Referral Services Network made up of 80 individual bilingual providers;
- increasing levels of cultural competency and HIV sensitivity among providers through training;
- bridging linguistic barriers through language interpretation by bilingual peer advocates (BPAs) and comprehensive case management by case managers.

The distinctiveness of this navigation model centers on its capacity to expand the range of HIV care to A&PIs living with HIV/AIDS without creating new ethnic-specific service sites. During its operation, the Bridges Project has been confronted by expected and unexpected problems in working to achieve its three primary goals, and its staff has learned valuable lessons in overcoming them.

Project Setting

The Bridges project at APICHA specifically targets A&PIs living with HIV/AIDS in the New York City metropolitan area, particularly those with limited or no English language capacity and who have difficulty accessing HIV-related services.

Unlike San Francisco and Honolulu, where Asians and Pacific Islanders make up 30 percent or more of the total population, they represent a relatively small segment of the citizenry in New York City: currently between seven and eleven percent. This, combined with the popular myth that Asians and Pacific Islanders do not experience social problems, tends to make them marginalized, even invisible, in the arena of medical and social services, despite the fact that in absolute terms, they constitute a large and growing community in New York City (687,547 strong in 1997).

A & PIs have a particularly difficult time accessing linguistically appropriate, culturally competent services because most hospitals, health clinics and HIV-related service providers do not allocate resources to provide

■ 29 Distinct Asian Groups

■ 20 Pacific Islander Groups

■ 100 Languages & Dialects

information or to meet the needs of this community. These shortcomings are compounded by the fact that A & PIs constitute a very diverse group.

Immigrants, migrants, and refugees make up 77 percent of NYC's expanding A&PI population. According to the 1990 U.S. Census, of that population, 47 percent are Chinese, 17 percent Indian, 14 percent Korean, 9 percent Filipino, 3 percent Japanese, and 2 percent Vietnamese. An additional 8 percent included Pakistani, Bangladeshi, Thai, Cambodian, Indonesian, Guamanian, and other rapidly growing communities. Forty-one percent of census-recorded Asian and Pacific Islander households in New York City are considered linguistically isolated, speaking little or no English. Fifteen percent live below the poverty level.

A&PIs with HIV/AIDS in NYC have a particularly difficult time accessing linguistically appropriate, culturally competent services because most hospitals and health clinics as well as mainstream HIV-related service providers do not allocate resources to provide information to and meet the needs of this community. These shortcomings are compounded by the fact that Asians and Pacific Islanders constitute a very diverse group, with 29 distinct Asian groups and 20 Pacific Islander groups speaking more than 100 languages and dialects.

According to New York City Department of Health statistics from September 1999, 58.5 percent of cumulative A&PI AIDS cases in NYC are known to be among immigrants or refugees, who generally have the most difficulty accessing mainstream services because of language and cultural barriers. This is certainly an underestimate, since for fully 22 percent of cases country of birth is unknown (19.5 percent are U.S.-born). The Health Department admits they haven't been good about collecting this information. The countries most heavily represented are the People's Republic of China (12 percent of all A&PI AIDS cases in NYC), the Philippines (11 percent), India (9 percent), Japan (6 percent), Guyana (4 percent), Hong Kong (2 percent), Taiwan (2 percent), South Korea (2 percent), Thailand (2 percent), Pakistan (2 percent), and Trinidad (2 percent) (Asians and Pacific Islanders from Guyana and Trinidad are probably south Asians).

Of those Asians and Pacific Islanders in New York City who have been diagnosed with AIDS, 53 percent of are gay, bisexual, and other men who have sex with men (MSM), 11 percent are women, and 12 percent are injection drug users. Unfortunately, many Asian and Pacific Islander-focused health and social service providers are blatantly homophobic and AIDS-phobic, woefully misinformed about HIV, and thus ill-prepared to work with clients who may come to them for information and treatment services. Even when health and social service agencies offer piecemeal HIV services, Asians and Pacific Islanders living with HIV/AIDS are wary of providers and unconvinced that confidentiality will be guaranteed. They are afraid they will see people they know when seeking services, both among staff and other clients.

...58.5% of cumulative A&PI AIDS cases in New York City are known to be among immigrants or refugees, who generally have the most difficulty accessing mainstream services because of language and cultural barriers.

Thus, while representing an expanding population with increasing needs for HIV-related services, Asians and Pacific Islanders are effectively prevented from accessing adequate services because of a number of barriers, including: lack of culturally competent, linguistically accessible, and HIV-sensitive providers; lack of coordinated primary care and case management services; lack of health insurance; distrust of institutions; and stigma within their communities surrounding sex, substance use, homosexuality, illness, and death.

Program Intervention

The overall goal of Bridges is to improve access to care by minimizing the impact of factors associated with service under utilization. Components of the intervention such as language interpretation and client advocacy, for example, address factors such as limited English proficiency, immigration status, and familial and peer support that can impede service use.

APICHA has linkages and referral agreements with a number of agencies and hospitals, many of which are Ryan White CARE Act grantees. Potential clients are referred to the Bridges Project by providers at service sites that are unable to provide the needed service primarily because of language and cultural barriers. When a client is referred to APICHA, he or she is assigned a bilingual case manager and, if necessary, a bilingual peer advocate (BPA) – who escorts clients to service sites and provides language interpretation and advocacy. In addition to helping service providers understand their clients' cultures, BPAs are able to explain the health care and social service systems to clients. They are paid, but work only part-time as needed. As a result APICHA is able to maintain a corps of 15 to 20 advocates speaking up to 12 Asian and Pacific Islander languages and dialects. In addition to being able to access services through linkage relationships, APICHA clients can also receive a number of in-house services, including full body acupuncture, free legal services, an Asian food pantry, and a range of culturally appropriate support groups.

APICHA's Education Department facilitated 371 workshops/rap sessions to 5,588 attendees and made more than 52,000 face-to-face contacts with Asians and Pacific Islanders in the past year. This extraordinary effort was implemented by 53 bilingual peer educators who were thoroughly trained and supported by professional staff. The department continues ongoing efforts to broaden the offering of HIV sensitivity trainings to non-linkage providers.

APICHA's technical assistance and staff training services have been provided free to all of the smaller community-based organizations in the Asian and Pacific Islander communities of New York. APICHA has provided workshops in harm reduction, health and sexuality issues, fund raising, presentation and facilitation skills, workshop development, immigration issues, media outreach, and leadership development. In APICHA's women's project domestic violence issues, self-defense, and safer sex negotiation have been the leading subjects of workshops. APICHA has reached out as well to gay activists and HIV/AIDS organizations in Burma, Korea, India and Thailand.

Extraordinary effort

In the past year APICHA's 53 bilingual peer educators have:

- facilitated 371 workshops/rap sessions
- presented to 5,588 attendees
- made more than 52,000 face-to-face contacts with A&PIs

What APICHA Has Learned

Ideally, any Asian and Pacific Islander immigrant living with HIV/AIDS in New York City would be able to access any needed HIV-related service in the language that he or she speaks. In this ideal situation, the service would also be provided in a way that recognizes the cultural practices and attitudes of the client or patient. Given a tight funding environment, a lack of prioritization and the numerous languages, national, and cultural groups that within the Asian and Pacific Islander communities, though, such an ideal is difficult to achieve.

The BPA program—which trains and maintains a corps of paid, part-time, bilingual workers to act as language interpreters, cultural guides, and client advocates for clients as they navigate the medical and social service systems—has demonstrated innovation in overcoming these barriers. It has also proven to be a cost-effective method for meeting the unique service needs of the community. Preliminary data indicate that the program has a positive impact on the service system and on client satisfaction.

One of the most striking facts to emerge from focus groups conducted on these issues is that neither case managers nor advocates have ever received a complaint from an outside service provider about their performance. An explanation for this, beyond the high quality of work of BPAs, is the great need of service providers to have a bridge to their clients. Service providers feel quite paralyzed and frustrated when they are confronted with clients with whom they are unable to communicate. The great need that service providers have for bilingual peer advocate services is a testament to the great difficulty immigrants have in accessing HIV-related services. As one advocate said, "Yeah, [outside service providers] appreciate [BPAs] because they have a difficulty communicating with the clients. So, they need us. They definitely need us."

Some real life situations illustrate this need. Another BPA reported, "...just as soon as I got to the hospital . . . the receptionist and the other nurse called me 'Come on, come on! Your client's in the waiting room!' ...Sometimes I couldn't believe [how] they just call me, 'hurry up,' ...without any checking out [who I am]."

She continued with another example: "Several times when I was waiting with a client . . . for too long for the doctor's appointment, I go to the nurse station to talk to them. 'I don't have time to wait here, I gotta go. Otherwise you have to find an interpreter for the patient.' Then the nurse will put the client [at the top of the list]. So it means that they really need us to give them the help. Otherwise they have a big problem. They have to . . . find another interpreter."

Aside from the confirmation that the Bridges Project is needed in the community, APICHA has learned some valuable things about how to best carry out our work. Three of the key lessons learned relate to (1) the prospects and pitfalls involved in establishing and maintaining formal linkages with comprehensive health-care service sites and developing a referral service network of medical and social service providers; (2) when and how to offer and carry out cultural competency training, and; (3) how to combine case management services and a bilingual peer advocacy program.

Lesson #1: A successful service network requires consistent efforts.

APICHA's Department of Client Services conducts regular client outreach to hospitals, clinics, and social service agencies. BPAs conduct the client recruitment/outreach work under the supervision of a linkage coordinator. The linkage coordinator visits at least two service sites each month to meet with staff and discuss APICHA's services. A large portion of the trainings is devoted to apprising linkage staff of the services provided through the Bridges Project. In addition to ongoing outreach, the trainings for linkage site staff serve as dissemination activities, during which a client services brochure printed in five languages is distributed to both service providers and potential clients.

Two activities seem to help most with ensuring that linkage relationships move from paper to reality. One is regular training provided by APICHA's diversity trainer. The trainer provides staff at linkage sites with information on APICHA's services and specifically on the nature of the linkage agreement. She also provides training on how to work with A&PIs living with HIV/AIDS and with the BPAs as language interpreters. The other activity that helps with maintaining a vibrant linkage relationship is cultivating working relationships among frontline service staff in both agencies. Frontline service staff members cross-refer and consult with each other more frequently if they are aware of the available services at the other agency, and then only if they feel comfortable with each other and confident in the services the other agency provides.

Lesson #2: Streamline trainings to make them more effective and useful.

Getting providers at other institutions to prioritize diversity training for their staff has been a challenge. Therefore, in addition to covering the components of the linkage arrangement with APICHA and the range of APICHA's services, HIV sensitivity training specific to the Asian and Pacific Islander experience is incorporated into the linkage site training sessions. The training sessions cover topics such as cultural competence, homophobia, cultural beliefs and practices and how they create barriers to accessing health care, how to develop culturally competent communication, and epidemiology and demographics.

Another difficulty is that providers seem to prefer a cookbook style training in which they receive hard-and-fast rules for dealing with Asians and Pacific Islanders from different language/ethnic groups. This approach is counterproductive since even within each language/ethnic group, there is vast diversity. To remedy this problem, training sessions are scheduled in smaller one to one-and-one-half-hour segments that follow in succession. The curriculum was modified to incorporate more of a didactic style interspersed with experiential exercises. Participants are walked through a chart listing common cultural characteristics of Asians and Pacific Islanders and how these characteristics play out in the area of HIV. The goal is to honor providers' need for concrete, useful information that can be applied in day-to-day work without oversimplifying the issue.

Lesson #3: Clear roles, specialized training and open communication help the program run smoothly.

Of APICHA's current 96 HIV-positive clients receiving comprehensive case management, 31 clients are being served by bilingual peer advocates; some clients need none because of their English fluency and some are awaiting recruitment of an advocate with suitable language skills. Each month, BPAs spend 8-12 hours working directly with clients, 3-5 hours conducting client outreach, 10 hours in travel, and two hours in training. They are provided clinical supervision by three full-time case managers and are paid because they commit more time to work and training than volunteers. BPAs start with a three-day, intensive training and then receive a two-to-three-hour, monthly follow-up training. They are expected to be available on a regular basis; some are on-call and carry beepers. BPAs work only part-time in order to retain a level of flexibility that full-time staff do not typically have. More importantly, part-time status allows APICHA to hire a broader range of individuals representing more cultures and languages. Currently APICHA maintains a corps of 18 bilingual peer advocates. Among them, they speak 10 major languages in addition to English: Cantonese, Mandarin, Toishanese, Japanese, Korean, Tagalog, Hindi, Bengali, Gujarati and Urdu.

> Peer advocates...have no office space. They are considered neither part-time staff, nor volunteers, nor independent contractors or consultants. Given their unique status, it is not always clear how to work with them and what to expect.

Because of the unique staffing structure introduced by the program, however, a number of difficulties in program implementation have arisen in the areas of role definition and supervision, training, and communication.

Problems of role definition

Peer advocates receive an hourly rate of pay and have no office space at the agency. They are considered neither part-time staff, nor volunteers, nor independent contractors or consultants. Given their unique status, it is not always immediately clear how to work with them and what to expect.

Some case managers express frustration over BPAs' lack of professionalism and their tendency to see themselves as volunteers. The advocates in turn, view their volunteer spirit as a positive quality that should be nurtured. Another point at issue is their role as translator. Case managers feel that advocates sometimes confuse their role by speaking for clients instead of allowing clients to speak for themselves. BPAs stress how difficult it is to do strict translation given the emotional context of HIV disease and clients' hesitancy to disclose personal information. They understand from their training that the ideal interpreter conveys the exact meaning, but they find this ideal hard to meet in the field.

Supervision, training and communication problems

Ambivalence about the role of bilingual peer advocates also gets expressed in discussion about whether a client is assigned a single advocate on a permanent basis or is served by many depending on availability. The system varies from case manager to case manager. Some case managers permanently pair a client with one person, while others rotate advocates among clients. BPAs agree that the ideal is a permanent one-on-one assignment.

Both case managers and BPAs expressed distress at the lack of preparation case managers receive to supervise a small team of BPAs. Case managers with more supervisorial experience seem to have smoother working relationships with the BPAs. In addition, the training peer advocates receive needs to be tailored to the their role. The most effective peer advocates seem to be those who understand the procedures of the agency, communicate regularly with the case manager, but also feel confident in using their own judgment. Those who work toward this type of stance feel very satisfied when the case manager supports them. Most feel that greater job satisfaction comes from developing a deep one-on-one relationship with clients, something that can occur only if they are not rotated among clients. Although they express frustration with case managers' seeming rigidity in enforcing boundaries, they understand the need for boundaries.

Despite the difficulties of working in this fairly unique staffing structure, those involved in implementing the program do not see the difficulties as outweighing the benefits. The effectiveness of the program is also corroborated by the high level of client and provider satisfaction. Still, the bilingual peer advocate program requires improvements, including:

- more support and training for case managers who supervise BPAs;
- permanent pairings between peer advocates and clients whenever possible;
- additional training to BPAs on boundary issues, advocacy and language interpretation;
- regular case conferences between case managers and BPA teams;
- clarification of roles and responsibilities; and
- cultivation of trust and communication through team-building and staff development programs.

While the ideal situation would be to have all needed services provided by those who speak the client's language and understand his or her culture, this is not always possible, particularly in tight funding environments and where racism, intolerance, or simple lack of awareness make such an ideal goal a very low priority. The bilingual peer advocate program provides a cost-effective option that ensures minority access lifesaving and life-enhancing services.

It is the hope that information presented here will be useful to those who might be interested in starting similar programs to serve the needs of language, cultural, racial, or ethnic minorities. The lessons learned from the implementation of the bilingual peer advocates program may be adapted to a wide range of service contexts in which a language/cultural/racial minority experiences barriers to accessing services, especially when this minority is heterogeneous and small relative to the larger population.

Summary

Current findings show that APICHA has been successful in reaching the immigrant A&PI population, as only 10 percent of clients were born in the U.S. Breaking the data down by citizenship status show that noncitizens/nonpermanent-residents have more barriers to accessing services than citizens/permanent residents. Thirty-one percent of noncitizen/nonresident clients report English fluency, but only 10 percent say they are comfortable negotiating their service provision in English. Seventy-two percent of citizen/resident clients report English-language fluency. Only 18 percent of noncitizen/nonresident clients report having a full-time job, while 36 percent of citizen/resident clients are employed full-time. Seventy-six percent of noncitizen/nonresident clients have a primary care physician, compared to 97 percent of citizen/residents.

Data also show that clients are accessing APICHA's services fairly soon after receiving an HIV-positive test result (although this does not necessarily mean that they are accessing care early, since they may not be tested early in relation to their date of infection). Nearly 38 percent came to APICHA within a month of testing HIV-positive and 52 percent showed up within three months of a positive test. Concerns about early access are especially important in light of recent New York City Department of Health AIDS surveillance statistics showing that Asians and Pacific Islanders and Native Americans have the highest rate of opportunistic infections at the time of AIDS diagnosis in comparison to other racial groups followed. Only 23.4 percent of those who sought APICHA's services within three months of their HIV-positive test result were asymptomatic at the time of the intake interview.

The Bridges Project Chronology

April-May 1996

- Model designed to create a comprehensive, integrated system of care for A&PIs living with HIV/AIDS. The model includes three main components: linkages with key providers, training of providers, and comprehensive case management utilizing full-time case managers and part-time bilingual peer advocates.

October 1996

- APICHA is awarded a SPNS grant.
- Begin recruiting staff for the Bridges Project.

December 1996

- APICHA's founding executive director resigns.
- Linkage coordinator hired.

February 1997

- New director of client services and Queens site coordinator hired.

March 1997

- Diversity trainer and research analyst hired.
- Linkage coordinator develops protocols for hiring, training, and supervising bilingual peer advocates. She also develops recruitment materials.

April 1997

- Two case managers hired.
- APICHA and the Bridges Project receive publicity through the local media, including articles in *World Journal* (Chinese-language), *New York Newsday*, and *The New York Times*, as well as a spot on Chinese-language cable TV.

May 1997

- Begin negotiating new linkage agreements with original six linkage sites established for the Bridges Project, in order to include a provision for the linkage sites to provide APICHA with data. Two linkage sites are reluctant to sign new agreement and insist on making the data requirement voluntary.
- Sixteen BPAs are hired. They include eight men and eight women, speaking Bengali, Urdu, Hindi, Punjabi, Sindhi, Telugu, Gujarati, Tagalog, Cantonese, Mandarin, Taiwanese, Korean, Japanese, and English.
- First version of the Bridges Project baseline-intake form is completed (goes through three more revisions to include core elements and other modifications before final version is settled on in late 1998.)

May-June 1997

- Pilot BPA training curriculum is completed and first three-day training takes place.

June 1997

- APICHA holds a public celebration at Queens Borough Hall to mark the opening of its new site, the APICHA Queens Community Center.

March-July 1997

- Research on potential sites for Queens office. Conduct meetings with community board and borough president to introduce APICHA. Lease for Queens site signed in July after long negotiation process.

October 1997

- Monthly follow-up trainings for BPAs begin.
- First linkage coordinator resigns. She is replaced in January 1998.
- Third case manager is hired.
- Training of staff at five of six original linkage sites is completed. The sixth linkage site does not respond to requests to train staff. Trainings end up being shorter than desired as linkage sites agree to only two- to three-hour trainings.

December 1997
- First client satisfaction survey conducted.

November 1997-February 1998
- Second three-day BPA training is completed for six new BPAs.
- Total pool of BPAs is 17.

March 1998
- First research analyst resigns. She is replaced in July 1998.

March 1998
- APICHA receives a Ryan White Title I award — hire fourth case manager.

April 1998
- APICHA receives federal certificate of confidentiality.

May 1998
- APICHA receives IRB approval, allowing collection of data that is not purely service-related.
- Focus groups conducted with bilingual peer advocates and case managers on program implementation issues.

June 1998 - present
- APICHA is required to implement the Uniform Reporting System (URS) by New York State and Title I funders. The database heavily overlaps with the Bridges Project database in development without meeting data collection needs. Ongoing work takes place to integrate the two databases and to allow data entry from both our Queens and Manhattan offices.

July 1998
- Director of client services resigns. Case manager is promoted into the position in October 1998, leaving a case management vacancy.
- Two new linkage sites added to the original six.
- Findings from focus groups with BPAs and case managers are presented in poster at the 12th World AIDS Conference in Geneva. Poster is then revised for submission to *American Journal of Community Psychology*. Summary of poster is published in *International Journal of Sexual Health*, special issue on peer-based interventions.

July-August 1998
- Third three-day BPA training is completed.

September-October 1998
- Refresher trainings conducted for three of original six linkages sites.

October 1998
- Team case conferences between BPAs and case managers begin every other month in response to feedback from focus groups.

November 1998
- One case manager resigns.

December 1998
- A senior case manager is hired through Ryan White Title II funds.

January 1999

- Two new case managers are hired to fill vacancies from one resignation and one promotion.
- Diversity trainer resigns.
- APICHA receives reapproval from IRB.
- Lead evaluation consultant relocates from Boston to New York City. New York-based data management consultant is hired to replace Boston-based consultant. Thus the evaluation team is completely based in New York City for the first time.

February-April 1999

- SPNS evaluation databases installed at APICHA for data entry.

March 1999

- BPA appreciation party takes place. BPAs are given certificates.

May 1999

- New diversity trainer hired after almost four months of searching.
- Evaluation team generates first data output, mostly baseline data.
- Redesigned program management structure to allow us to engage in better program planning and provide more consistent supervision.
- Evaluator left. New evaluator hired.
- New half-time research assistant hired to help with data collection and data entry.

July-August 1999

- Three-day training conducted for nine new BPAs.

September 1999

- APICHA hosts second East Coast Conference on AIDS in Asian Communities. Offered two provider trainings on providing case management services for A&PIs with HIV.
- Discontinue relationship with one linkage agency because it has not been open to receiving training from APICHA.

October-December 1999

- Finalize linkages with three new sites, all of which serve A&PIs with HIV.
- Cultural competency trainings held at two hospitals.
- Referral Services Network database completed. Provider information entered on more than 80 providers.
- Design new service utilization form for BPAs, whose work is not tracked adequately by the existing form.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Bridges Project and the service delivery model APICHA has developed, please contact the project director:

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Houston MDI Project, Houston Regional HIV/AIDS Resource Group

A Continuum of Care for the Houston Homeless

Authors: Deborah Scott, Michael Springer and Stephanie Kim

Introduction

In Houston, Texas, there is a fissure among treatment providers regarding HIV and substance abuse. The problem is one echoed throughout the country—the question of the efficacy of HIV treatment and medication for active substance abusers. Most providers are well versed in HIV treatment but hesitant to bridge the gap between the dual issues of substance abuse and HIV. This hesitancy has led to a lack of providers for this difficult-to-treat population. Additionally, housing providers prefer to offer shelter to those with less complicated health and social problems.

By providing a continuum of care ranging from initial crisis intervention to assistance in securing permanent housing, the Houston MDI Project attempts to minimize barriers to services faced by homeless men and women who are HIV positive and struggling with substance abuse/mental illness. The project strives to engage clients in a process of long term, comprehensive care. This model allows clients to receive a comprehensive range of services including medical stabilization and chemical dependency treatment.

Over the past three-and-a-half years, the project has learned a number of instructive lessons on how to work with multiply diagnosed clients, medical providers and the social service community. A brief overview of the project as well as some of the lessons learned are highlighted here.

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Location

The Houston MDI Project addresses the need in Harris County, Texas, for housing for homeless HIV-positive individuals, especially those with complicating health issues such as substance abuse and mental health.

Services

The Houston MDI project offers the following services: immediate referral services and access to transportation to housing through a crisis hotline staffed by Crisis Intervention; medical stabilization and short-term housing through the Houston Recovery Campus; case management and long-term counseling through the Montrose Counseling Center; long-term residency treatment through Project LifeRoad; creation of an AIDS/HIV-friendly housing data base for long-term housing referrals through Houston HIV Regional Resource Group; and deposit assistance for long-term housing through The Bering Omega Community Service. It is through the collaboration and participation of agencies with varying expertise that the project can provide this continuum of services. The Houston Regional HIV Resource Group is the administrative agent for this collaboration and also serves in that capacity for other Titles II, III and IV projects, providing administration for the Title II Consortium and sitting on the Title III Ryan White Planning Council.

Lessons Learned

Lesson #1: Take an inclusive approach to linkage building.

In order to provide clients with the wide range of services required, the project needed to collaborate with other agencies. Project developers determined that it was not feasible for one mega agency to provide all of the services necessary. The Houston MDI Project's executive director, who was well known in the community and had built relationships with numerous other organizations, greatly facilitated initial collaboration efforts. This director took an inclusive approach to linkage development upon the release of the funding opportunity.

> Members of the service provider community had been aware of the gap in services.... (so there) was tremendous response to the call for action.

Members of the service provider community had been aware of the gap in services for individuals with a dual diagnosis of substance abuse or mental illness and HIV. When the Houston MDI project identified an opportunity for funding to address this need, all service providers in the Houston area were invited to a community meeting. The purpose of this meeting was to explain the project, allow all agencies to introduce their services, and seek the participation of agencies interested in collaboration.

There was tremendous community provider response to this call for action. Meeting participants formed a work group to determine how interested agencies could come together in to provide a continuum of care that would fulfill the goals of the grant. Ultimately, of the more than 30 original agencies at the first meeting, the majority self-selected out of the project either because their service was not an easy fit or the funding was too restrictive. Agencies that opted to participate tended to be already providing compatible services. For example, one organization had been delivering hotline services to the general community for many years and partnering with the project would be another means to promote the existing agency mission. Another organization had a history of administering subsidy funding and had protocols in place to deliver this service.

The credentials of the Houston Regional HIV/AIDS Resource Group helped establish credibility. The Resource Group had established community linkages and was recognized as a network builder and could draw on many established formal and informal partners to create a unique continuum of care. The Resource Group also brought significant experience in providing well-established in-house services (data management, financial management, programmatic oversight, evaluation/planning) necessary for a successful network formation and operation.

The Houston MDI Service Continuum

In order to provide clients with a wide range of services, the project collaborates with many other agencies. Solid linkages are the cornerstone of service delivery.

- transportation to housing
- medical stabilization
- short-term housing
- case management
- long-term counseling
- long-term residency treatment
- AIDS-friendly housing database
- deposit assistance for housing

Lesson #2: Modify program structure to meet client need.
A program must be flexible enough to change in response to client needs. Continuing evaluation is critical in this process.

The project initially developed a linkage with the Bering Foundation, whose role was to provide rental apartment and utility deposits after clients left short-term housing and medical treatment at the Houston Recovery Campus. This linkage did not work as planned. By the second year of the project none of the funds for housing deposits had been accessed. Clients were not accessing the deposit funds because they seldom sought independent housing, preferring instead to go to the home of a relative or friend. Prior to releasing funds the Bering Foundation required that an applicant be able to show some form of income enabling maintenance of the apartment. More often than not, individuals were unable to show proof of such income. As a result the linkage between the project and the Bering Foundation was reduced in scope and funding. The project instead invested targeted deposit funds into long-term housing providers after this need was formally identified in the process evaluation. The project developed a linkage with Project LifeRoad, which provided long-term housing and substance abuse counseling. During the third year of the program, clients that were completing an extended stay at Project LifeRoad were able to gain employment and then qualify for deposit funds. This program change allowed clients to stabilize in long-term housing and then move on to independent living. Funds in the third year were reappropriated to the Bering Foundation in response to these successes.

Lesson #3: Facilitate communication between agencies.
Communication between both providers at agencies and providers and clients is essential to smooth operations. If agency staff is not familiar with services provided by partnering agencies, clients might be prevented from accessing key resources. To avoid this and other communication difficulties, the program institutionalized monthly meetings between all partners to help clarify and communicate project status. These meetings helped the project avoid major conflicts and aided in ensuring smooth referrals between program clients.

Communication between providers and clients is also important, especially in reference to case management services. Case managers from the various AIDS service organizations with clients admitted to the Houston Recovery Campus MDI unit were contacted and asked to attend staff meetings regarding the service plans for their clients. Most case managers did not participate in these meetings, due for the most part to a poor relationship or history with the Houston Recovery Campus as a whole. Case managers could not distinguish the MDI unit as a unique program and different from units elsewhere on the Houston Recovery campus. To solve this problem, joint staffing was proposed between the Recovery Campus, the Resource Group and Montrose Counseling Center on a weekly basis. Those clients with unresponsive case managers, or those with no case managers were referred immediately to the case manager from Montrose Counseling Center who could schedule time with the client. This joint staffing structure ensured clients did not get lost in the system after entering the Recovery Campus for services.

Another communication problem arose related to the linkage between the AIDS Service Organization and Crisis Intervention. The role of Crisis Intervention was to field calls from individuals requesting housing referrals when the Houston Resource Group was closed. Although the linkage was formalized, the other partnering agencies in the program did not know about the services of Crisis Intervention and consequently clients were not instructed to call, resulting in an underutilization of services. To better acquaint the project's linking agencies with the program, in-service staff meetings were held at Crisis Intervention, literature was distributed to agency staff and agencies were encouraged to distribute it to their clients. Crisis Intervention's role might change somewhat in future as the project attempts to link with the Harris County Jail. Crisis Intervention would have the specific task of contracting for taxi service to transport released inmates with substance abuse issues and HIV directly to the MDI unit.

Lesson #4: Technology does not necessarily make tracking easier.

Initially, Houston Resource Group created a database that tracked HIV-friendly housing and documented the requirements for getting into apartments. This database was updated on a quarterly basis and maintained electronically. It was anticipated that staff from the different AIDS service organizations would call the Houston Resource Group telephone referrals for their client.

Tracking of referrals proved difficult to track. Once case managers knew who to call for their clients, they circumvented the call to the Houston Resource Group. To remedy this, a hard copy of the directory was published and distributed to case management staff throughout the area. Each agency receiving a directory was asked to complete a usage log each time a client was referred to a housing provider identified in the directory. Hard copy updates were promised to agencies completing the log. While the directory was apparently well utilized and there were frequent requests for additional copies, there was no effective method of maintaining usage.

Houston MDI Project Chronology

January 1996

- Anecdotal observations of the increased need for mental health services for HIV-positive individuals.

February 1996

- Release of Request for Proposals (RFP) and convening of an organizational meeting to identify possible partners.
- Workgroup drafts proposal.

September 1997

- Project receives notice of award.

March 1998

- Program begins.
- Partner meetings held on a monthly basis.

April 1998

- Routine staffings institutionalized.

July 1998

- Housing database created.

February 1999

- Project staff learns that one location's rental subsidies are underutilized.

April 1999

- In-service staff meeting held.

May 1999

- Hosted meeting with case managers to promote the underutilized location's services.

September 1999

- Hard copy of housing database is distributed to agencies.

January 2000

- The Resource Group conducts a site visit of an outside project.

March 2000

- Outside project added as a partner.

September 2000

- Received continuation funding.

Further Information and Technical Assistance

Should you wish to obtain additional information bout the service delivery model developed by the Houston Resource Group, you are welcome to contact the project director and request technical assistance:

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Jefferson Comprehensive Care Systems, Inc.

Creating a Service Continuum

Authors: Angela Smith, John Wayne, Bhadra Kleinman and Robert Sember

These lessons are drawn from the first four years of this initiative's five-year grant cycle and represent experiences during the implementation and refinement phases of the project. Information from the outcome phase of the project will be available in Fall 2001.

Introduction

AIDS is a complex condition characterized by multiple needs. It is now generally recognized by medical and social service providers that because of the multifaceted nature of HIV illness, circumscribed medical models are seldom effected in providing standards of care to persons who are HIV positive or have AIDS. Often in traditional systems of care there is little connection between medical and social services, clinical specialties operate relatively independently of each other, and patients are expected to follow precisely defined protocols in both their approach to and compliance with care.

Persons living with HIV/AIDS often confront intrapersonal and environmental challenges that make it difficult for them to seek care within traditional systems. These challenges range from keeping medical appointments, to managing the emotional stress associated with chronic and terminal conditions, to adhering to the complex protocols governing the use of advanced retrovirals and combination therapies.

The Arkansas HIV Care and Support Network project was designed to implement and evaluate two models of blended care in which enhanced case management, psychosocial services, and skills building and enrichment activities support individuals with HIV/AIDS throughout the continuum of medical and social services. The

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progress of clients served in these two models is compared with the progress of clients seen at a more traditional ambulatory health care delivery site.

Location

Jefferson Comprehensive Care Systems, Inc. (JCCSI) provides services to persons with HIV/AIDS living in southeastern Arkansas. This predominantly rural area consists of eight counties that include among other areas of the state, the impoverished Arkansas Delta region. Only two of the eight counties contain urban centers. The remaining six counties have been designated as medically underserved areas (MUA) by the U.S. Health Resources and Services Administration (HRSA). The region may be generally characterized as one of severe economic and social distress, with low education levels, high rates of teen pregnancy and a large number of single parent families.

As in most regions of the U.S., Arkansas minority populations living in poverty are disproportionately infected and affected by HIV/AIDS. While African Americans comprise 16 percent of the state's population, as of 1997 they accounted for 45 percent of all HIV cases and 41 percent of all AIDS cases (Arkansas Department of Health). The remaining infections occur among the state's white, Latino, Asian American and Native American populations. In 1992 in the JCCSI service area, African Americans comprised 34 percent of the population and 67 percent of the reported HIV cases. In 1995, 70 percent of newly reported HIV cases occurred among African Americans. This epidemiological profile is reflected in the clients served by JCCSI, 71 percent of whom are African American and 29 percent white.

Client profile

74%	Male
74.5%	African American
36	Average age
6%	Married, live with spouse
18%	Employed

Based on data from 71 clients at both sites collected between May 1998 and June 1999.

Services

The Arkansas HIV Care and Support Network project operates from two sites in the agency's catchment area, the cities of Pine Bluff (Jefferson County) Little Rock (Pulaski County). These cities are approximately 50 miles apart. This project operates three models of care across the two sites –a traditional ambulatory health care delivery model, located in Pine Bluff and two enhanced delivery models, located in Little Rock.

Traditional ambulatory care models

The traditional ambulatory health care delivery site at the JCCSI's Pine Bluff offices is a clinic based program providing a comprehensive range of primary health care services, including laboratory monitoring, case management, HIV counseling and testing, medication assistance, nutritional counseling, dental care, health education, gynecological services, family medicine and referrals to mental heath and substance abuse services.

Enhanced delivery models

The enhanced models implemented in Little Rock are blended care systems characterized by one-stop shopping and aggressive client case management. Both models include a full compliment of medical and supportive services. A series of skills building activities offered to the one group distinguishes it from the other.

Services are provided on the University of Arkansas Medical School (UAMS) campus and at the HIV Care and Support Network program's administrative office. These locations are within walking distance of each other. Clients receive medical care and some level of health education on medication adherence at UAMS. At the program offices, clients meet with an outreach case manager. When they first enroll in the program, all clients receive a psychiatric assessment.

Clients enrolled in the enhanced model group with skills building activities have access to a well-equipped gymnasium; monthly social gatherings, support group meetings and lectures on relevant topics; computer training; and quarterly field trips. These elements are offered with the intention of increasing clients' knowledge and self-esteem, and reducing the loneliness that often accompanies advancing AIDS. In addition to the initial psychiatric assessment, all clients in this group receive continuing mental health follow-up every three to six months.

Evaluation

The comparison between the blended and the traditional health care delivery models is designed to assess the impact of systems level intervention on clinical and psychosocial outcomes of HIV-positive clients. The comparison between the two models at the blended model is designed to assess the impact of clinic level interventions. At the time of publication, data collection at all three sites continues. Outcomes findings from the comparisons will be available once the data collection is complete and the data are analyzed. While preliminary trends are reported below, the following lessons are drawn from experiences during the implementation and refinement phases of the project.

Ensuring Client Participation

Work with the clients in the program has been characterized by a number of difficulties. These include both environmental problems, such as a lack of resources, and individual characteristics, such as a lack of motivation or persistent depression. If unchecked, these problems inevitably result in clients not adhering to treatment protocols and ultimately dropping out of care altogether. To respond effectively to these difficulties and minimize the drop-out rate, program staff have developed a number of strategies: they use intimate knowledge of their clients' lives to increase rapport; they work together to monitor and share information on client activities in the many components of the program, and they provide a range of incentives to increase participation in activities.

Lesson #1: Knowing the clients helps build effective strategies.

In order to build effective rapport and trust, program staff must meet clients in the context of their crisis. That is, staff must understand what HIV/AIDS means to the clients and how their HIV infection and illnesses relate to their lives overall. This enables staff to identify client specific needs and to assist each client access services in a way that is effective for him or her.

Managing competing responsibilities

Program staff have learned that a primary component of effective case management is acknowledging that clients have other responsibilities. Staff help clients manage both their HIV/AIDS related responsibilities, such as making appointments and adhering to treatment protocols, in a way that does not create conflict with other activities, like caring for children.

> In order to build effective rapport and trust, program staff must meet clients in the context of their crisis.

Need for ancillary services

Complementing the efforts to help clients manage their various responsibilities, is the project's increasing awareness of the needs clients have for services beyond the traditional HIV/AIDS clinical services. The project evaluation data shows that the majority of the clients experience mental health problems. In response to a survey of needs, 59 percent of the clients who responded reported emotional or psychological problems in the last six months, 90 percent of those experienced difficulties getting help for these problems. Other substantial problem areas are housing and transportation where 60 percent of clients surveyed needed assistance with housing problems in the last six months and 73 percent needed assistance with transportation in the same period. All three of these areas of need, mental health, housing and transportation, have a direct impact on the ability to access and maintain care.

To ensure adherence, the project had to address ancillary needs because within the last 6 monts: 59% reported emotional or psychological problems; of those, 90% had trouble getting help; 60% needed help with housing problems; and 73% needed assistance with transportation.

Clients cycle in and out of services
Familiarity with the contexts within which clients experience their HIV infection has also increased the project staff's acceptance of the fact that the patient population is very mobile and that clients are likely to cycle in and out of the program or to leave permanently at some point. Incarceration is a common reason for dropping out of the program for a period; more than a quarter of the clients (27 percent) have been incarcerated at some point in their lives. Because of economic, legal and family reasons, individuals in this population are also likely to relocate and to drop out of care. In order to determine the most effective intervention, it is important that staff have the skill and background knowledge to determine why a client is not active in the program.

Lesson #2: Sharing information and working together adherence increases.
Having thorough documentation is an essential element in delivering an effective program and demonstrating outcomes. By recording program activity, staff are able to share client progress and difficulties with the service team. Consequently, the staff can work together to resolve difficulties,

Tracking system
JCCSI has developed a detailed tracking system that allows a case manager to interact with clients regarding all aspects of the continuum of care. The primary component of this system is a master list containing each client's contact information, information on his or her provider and a list of medications she or he is taking. The staff also obtains progress reports and clinic visit charts on each appointment to monitor the status of clients. By accessing the reports staff members can be informed of any health concerns or improvements, and possible recommendations.

Communicating with clients
The tracking system includes protocols for communicating with clients. Each client is contacted by phone once a week and monthly home visits are made when possible. The case manager and outreach counselor remind clients of clinic visits, dental appointments, therapy sessions, etc. If needed, staff members also provide transportation to and from all appointments. Providers notify the program when clients do not show for appointments. The case manager and outreach counselor immediately attempt to contact the patient, obtain information regarding the missed appointment, and reschedule for the next available appointment date.

Increased adherence
This proactive approach is the foundation to an increased partnership among program staff and between staff and clients. The morale of the program staff increased as a result and it has become easier to intervene with clients who experience difficulty adhering to treatment. In conjunction with close follow-up, home visitations and regular phone calls, the recreational activities in which some of the clients participate have improved their physical, mental and social outlook. Preliminary evaluation findings indicate that this may, in turn, increase adherence. Between baseline and follow-up data collection periods, adherence increased for clients enrolled in both of the Little Rock based enhanced service delivery models. The greatest percentage increase occurred in the clients who also participated in the skills building activities—their adherence rates rose from 67 percent at baseline to 94 percent at follow-up. Adherence in the other group rose from 56 percent at baseline to 67 percent at follow-up. Between baseline and follow-up the average CD4 count increased and the average viral load decreased for clients in both of these groups.

Lesson #3: Incentives increase participation in data collection.
The evaluation of these intervention models is necessary in order to demonstrate their relative strengths and weaknesses. When enrolling in services, clients are asked to also participate in the evaluation study. It has

been difficult to persuade eligible clients to participate given the mistrust of research and the length of time required to respond to the evaluation surveys.

Staff have tried a number of strategies to increase participation. The most effective has been the use of incentives. Clients are given $5 Burger King or Wendy coupons for each segment of the data book they complete. Once a full dataset is complete, they are given $20 Kroger or Walmart gift cards. Working to increase client participation and involvement in program planning, especially the social and skills building activities, has also helped build trust and a deeper investment on the part of clients in their own well-being and the health of the project.

Implementing a Demonstration Project

From its inception, The HIV Care and Support Network project has experienced a number of unanticipated barriers to implementing and refining the program. These difficulties have occurred at systems and administrative levels and must be distinguished from the client-level barriers detailed above, although they have affected the project's ability to work with clients. Among the areas in which the project experienced difficulties are changes in collaborative partners, the design and implementation of the evaluation design and access to clinic facilities. From these experiences lessons mat be drawn concerning, effective early planning, the development of collaborative partnerships, and the need for systems to deal with unexpected events.

Lesson #4: Allow adequate implementation time.

It takes six months for the basics

It takes a great deal of time and effort to implement a new program. Anticipate a minimum of six months to put the basic elements in place and at least a year before all program components will be established. During the second year, basic problems can be resolved so that by the third year the program will be running at the level anticipated in the proposal, although continued refinements will be required.

Set realistic goals and objectives

A complex intervention model will need to be built over time. By not taking the time to secure each component of the project, it is inevitable that the program will run into difficulties at some point in time. Obtaining IRB approval was one of the most difficult tasks for this program. Given that in a demonstration project services and evaluation are inextricably linked, the IRB difficulties severely curtailed the implementation of other program components. Having the guidance of individuals with experience in these kinds of activities can smooth a difficult path.

Identify key staff early and minimize turn over

Staffing proved to be one of the most troublesome areas for this project. Hiring and recruiting key staff is time consuming. In order to reduce delays during the initial stage of implementation, identify all staff in the grant application. Some staff turn over is inevitable. One of the surest ways to minimize this turn over, however, is provide a good working environment and compensation appropriate to the abilities and qualifications of staff.

Lesson #5: Developing and sustaining strong collaborative relationships is essential.

Attaining formal support for the program from the administrators of collaborating agencies and institutions is very important. The support of personnel at UAMS, the primary collaborating institution, has been critical to the survival of the project.

Meet regularly

Program staff laid a strong foundation for the collaborative work from the beginning of the initiative by meeting with key directors from the Division of Infectious Diseases and hospital administrators. In these initial meetings the program was discussed in detail, transforming it from its proposed form into a plan that reflected the interests and approaches of both parties. The discussion covered program logistics, program goals, target population, evaluation designs and methods, eligibility, benefits, and anticipated outcomes. In monthly meetings, representatives from both agencies meet to address the day-to-day issues required to maintain the partnership and to ensure that the program following appropriate procedures.

Lesson #6: Have a backup plan.

Within the first 12 months of implementation, this project experienced two devastating blows. A tornado destroyed the building housing the enhanced treatment site; and the principal investigator, who was also an infectious disease physician, was removed from the project. Both events delayed the project implementation, illustrating the need for contingency plans to address unexpected problems with critical program components.

Following the tornado, the program staff was faced with the task of identifying an alternate location in which to provide services. That took close to four months. Settling into this new space required additional time.

The loss of the principle investigator (PI) contributed greatly to the delay in receiving IRB approval. In addition to the time taken to identify a new PI, key components of the program were changed which required a revisions to the evaluation plan. Consequently, a new research protocol had to be reviewed by the IRB. While neither the tornado nor the change in PI could have been anticipated, having other components of the project in place, ensured that progress could be made with other components of the program.

Jefferson Comprehensive Care Systems, Inc. Chronology

October 1996

- Jefferson Comprehensive Care System, Inc. (JCCSI) became the recipient of a Special Projects of National Significance (SPNS) Program grant.
- Model designed to implement an innovative blended system in partnership with the Arkansas Department of Health (ADH).

March 1997

- Tornado destroys clinic where enhanced service delivery models are to be implemented. The most pressing goal is to restore access to services for existing patients.
- Identifies temporary space at the ADH's Central STD Clinic in Pulaski County.

May 1997

- Hire program coordinator.

June 1997

- Principal investigator identifies alternative space to place staff.
- Options consists of obtaining space in an existing community center or development of temporary space (module units) until such time the clinic facility can be rebuilt.

July 1997

- Decision made to obtain space at existing location, East End Community Center, with administrative office space held in an office building nearby.
- Program coordinator hires activity director and outreach counselor.

November 1997

- Institutional Review Board (IRB) approves research protocol.

December 1997

- Principal investigator (PI) removed from project resulting in loss of psychiatrist and program evaluator.
- Agency searches for a new PI, evaluator, psychiatrist for the project.
- Seek additional partnerships with Baptist Hospital and University of Arkansas Medical School (UAMS).

January 1998

- Find administrative office space.
- Meet with key UAMS officials who verbally commit to collaborating with JCCSI.
- Due to the PI removal, JCCSI has to submit a new protocol to the IRB.
- Prepare questionnaires for data collection.

March 1998

- IRB notifies JCCSI to obtain single project assurances (SPA) for off site institutions.
- Contract signed by UAMS.
- Pilot test questionnaires.

May 1998

- Co-investigator at UAMS writes a letter seeking permission to start study in Little Rock. IRB grants partial approval to begin the research study at the experimental site only.
- Receive single protection assurances and submits them to off site locations for signatures.

June 1998

- Receive signed SPAs from off site location and submits them to the IRB for signatures after which they are sent to the Office of Protection for Research Risk (OPRR).

July 1998

- Obtain SPA approval from the OPRR with stipulations to obtain a certificate of confidentiality.
- Receive letter from IRB restricting initiation to begin study in Pine Bluff (the control site) until certificate of confidentiality is approved.
- Social worker resigns.
- Activity director resigns.
- Post vacancies and interview candidates.
- Hire activity director and case manager.

August 1998

- Outreach counselor resigns.
- Post vacancy and hire outreach counselor.
- Halt enrollment for one month due to new staff orientation and program revisions.
- Revise data collection and attrition protocols.

September 1998

- Restart the client enrollment process; begin home visits and skills building activities.
- IRB informs JCCSI to stop study at the experimental site until receipt of the certificate of confidentiality is granted.

October 1998

- Receives certificate of confidentiality and full implementation rights to begin study.

November 1998

- Re-enrollment begins in Little Rock and Pine Bluff.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Arkansas HIV Care and Support Network project and the service delivery model, please contact the project director:

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The Tri-County Collaboration Project, University of Washington

Cross-system Training Builds Agency Capacity

Authors: Victoria Harris, Karina K. Uldall, Reema Rafii, Shelley Tonge and Peter Messeri

This article chronicles some of the lessons learned from the Tri-County Collaboration Project developed by the Center for Health Education and Research (CHER), University of Washington. This information is based on the project's experiences during the first four years of a five-year demonstration grant. Final results of the evaluation will be available upon completion of the grant during Fall 2001.

Introduction

Mental illness, chemical dependency and incarceration present formidable challenges to the already difficult task of providing appropriate medical care for HIV-positive individuals. Providers in one service domain or system (e.g. medical care of HIV disease) all too often lack the professional expertise to manage the added service needs of multiply diagnosed (e.g. chemical dependency, mental illness) individuals.

Various models of service integration have been advanced to overcome the formidable barriers to cross system collaboration. The one-stop-shopping approach brings together a multi-disciplinary team of providers from several agencies so that the necessary specialized services to care for multiply diagnosed individuals are available at a single location. Other models attempt to improve service integration through bilateral linkage agreements between agencies from different service domains (a medical care provider and mental health agency) that serve the same community. These models are most feasible for geographically small and densely populated urban communities with a high concentration of multiply diagnosed populations.

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> The project has concentrated most of its efforts on building capacity of agencies with existing HIV-positive client caseloads.

The Tri-County Collaboration has developed an alternative model for improving cross-system collaboration among agencies serving a geographically dispersed region that might include both urban and rural communities. The Tri-County model is based on a multidisciplinary "mobile" team that offers partner agencies clinical consultation services, technical assistance and professional training. The services of the mobile team are time delimited. The mix and intensity of services provided by the mobile team are flexible. Services are customized to suit the type of capacity building needs of each agency. The objectives of the Tri-County mobile team are to link multiply diagnosed individuals to care, to build agency capacity that best serves the special needs of this population and to facilitate enduring interagency collaboration that cuts across disciplinary boundaries that too often segregate one service system from another.

Over the last four years, the Tri-County Collaboration has learned a number of instructive lessons about both the strengths and limitations of a mobile team model for increasing the capacity of HIV and mainstream service providers to care for HIV-positive individuals who also suffer from mental illness, chemical dependency and/or are currently incarcerated. A brief overview of the project as well as some of these lessons is highlighted here.

Location and Target Population

King, Snohomish, and Island Counties were chosen for the geographic domain of this project, as they constitute the Seattle EMA for Title I of The Ryan White CARE Act. The three counties cover an area of approximately 4,510 sq. miles. As urban, suburban and rural counties respectively, King, Snohomish, and Island vary accordingly in the availability of health care resources. Most tertiary treatment centers in the region are located in King County, which is also the site of Washington State's only medical school. HIV specialized services also are concentrated in King County. Snohomish County is served by two community hospitals and two tertiary hospitals, yet it is designated a primary care professional shortage area. Island County is served by a single community hospital. Both Snohomish and Island Counties have minimal social support and housing for persons living with HIV.

An estimated total of 6,638 persons with AIDS live in the Tri-County region. Project staff estimate 35 percent of the HIV infected population in the Tri-County region suffer from mental illness and 85 percent of the HIV infected population in the region have active substance abuse issues. At any one time, as many as 100 HIV-positive individuals are confined in the King County Correctional facility. Many incarcerated individuals also have mental illness problems or are struggling with chemical dependency.

An agency inventory conducted by Tri-County staff identified more than 172 agencies that were potential clientele for mobile-team services. At the start of the project, interagency linkages across care systems were sporadic, largely informal and ad hoc in nature. In addition to the lack of continuity of care across systems associated with weak interagency linkages, care of HIV-positive patients with multiple diagnoses further suffered from provider ignorance and negative attitudes combined with inadequate treatment resources. Given the magnitude of the problems among agencies with HIV-positive clients, the project has concentrated most of its efforts on building capacity of agencies with existing HIV-positive client caseloads. On a more limited basis the mobile team has worked with mainstream agencies that previously have not served HIV-infected individuals. Active partner agencies in the collaboration include county jails, drug treatment services, community mental health centers, specialized HIV/AIDS housing agencies, local departments of health and primary medical care providers.

Services

The Tri-County Collaboration has chosen to address the challenges of linkages, staff training and resource enhancement through the creation of a mobile team of HIV/AIDS experts. The staff of Tri-County Collaboration are from the University of Washington Department of Psychiatry and are members of the Center for Health Education and Research. Members of the mobile team include two psychiatrists, a nurse practitioner and a chemical dependency specialist. Each member has considerable experience in both HIV and one or more of the component disciplines of the team. The team's most distinctive features are geographic mobility and the breadth and flexibility of services the team is able to provide to client agencies. Team members go to the agencies in need of their services. The mobile team has entered into various arrangements with area service providers that range from one-time on-site professional training program to extended periods of outstationing of mobile staff who provide both technical assistance and some direct client services to multiply diagnosed individuals. During the course of the project, mobile team members have provided:

- outstationing of psychiatrist for client assessments at county jail;
- oustationing of nurse practitioner at supportive housing program and primary care facility;
- oustationing of chemical dependency specialist at drug treatment program to extend services to include case management and long-term housing for clients;
- onsite client and provider focus groups at needle exchange program to assess need for case management services;
- training programs for mental health providers on caring for HIV/AIDS multiply diagnosed clients;
- twice monthly onsite clinical consultations at county health district offices;
- technical assistance to develop HAART protocol and assist in grant writing.

Lessons Learned

Lesson #1: Basic structure issues need to be addressed first.

In the formation of a mobile team, it was critical to include a chemical dependency specialist. The lesson was apparent with analysis of baseline agency surveys. Chemical dependency agencies uniformly knew the least about HIV primary care, mental health and criminal justice agencies. Thus, a chemical dependency specialist was found to be crucial in working with chemical dependency agencies. Other positions on the mobile team were set *a priori* and were found to be sufficient for training, technical assistance and chemical consultation requests.

Clinical Consultation Services

Under the auspices of the University of Washington School of Medicine, the entire project had to be declared a "site of practice" within the Department of Psychiatry prior to any clinical consultations. In addition, the Assistant Attorney General's office had to approve all cooperative agreements and memoranda of understanding. As direct clinical services were provided by faculty of the School of Medicine, issues such as liability, malpractice insurance and supervision for anyone other than a physician had to be arranged.

Lesson #2: Publicize mobile team activities to gain agency interest.

Cooperative agreements, memoranda of understanding and support letters provided a strong foundation for close and positive working relationships with several agencies in the tri-county region. Documentation of the agreements between an agency and the Tri-County Collaboration came only after extensive meetings. These meetings consisted of both agency administrators and project staff. The scope of services was discussed, as were potential difficulties such as client emergencies, and clients who live in one county, but receive care, or are incarcerated, in another.

Using the *SPNS Connection* newsletter was a highly effective method of publicizing the mobile team. Brochures advertising the mobile team, and specifically targeting providers and consumers, were also effective. Plastic key chains with the project name and contact information were distributed at an annual Seattle/King County Gay Pride Festival. A web site to publicize partnering agencies was created after the mobile team was well-established. Upon completion, a paper copy of the site was sent to all correctional facilities since web access at these sites is generally unavailable. The web site was both beneficial and resource-intensive. Agencies continued to call the mobile team for referral information even after the web site was constructed. It appeared that such a site might have some interest to agencies, but the level of utilization might not justify the resources necessary to maintain it.

Lessons #3: Provide the right kind of training and assistance for partner agencies.
From initial evaluations it became clear that staff from chemical dependency agencies were not attending training sessions. Future trainings were then designed to target this service domain. Participants most enjoyed and benefited from a clinical case presentation, followed by small group discussions. The groups were constructed so as to contain a mixture of agency and consumer representatives.

Evaluations found additional evidence that providers in rural areas and correctional facilities continue to be marginalized from training opportunities. Fundamentally a resource issue, providers in these locations generally lack computer access, are on contract and are responsible for their own continuing education and lack coverage when staff members attend trainings.

In general, agencies were not interested in assistance with policy development. While a hospital-based chemical dependency in-patient unit received extensive technical assistance on pre-and post-HIV test counseling and documentation standards, changes were not implemented due to staff resistance. Likewise, attempts to facilitate the design and implementation of a HAART protocol within a county jail was stymied by turn-over of key staff.

Some agencies that requested client evaluations/consultations were unable to provide for ongoing care once the client had stabilized. In general, when a client had a major mental illness that required a sophisticated approach with medications, agencies were reluctant to either accept ongoing care, or to formalize relationships with other agencies that could provide service. However, some agencies were able to effectively use process evaluation materials provided by the Tri-County Project to garner Title I or II Ryan-White monies for providers with needed expertise.

Tri-County Collaboration Project Chronology

November 1996

- Receipt of award notification.

January 1997

- Operationalize working definitions.
- Use of key informants to identify more than 300 eligible agencies.
- Develope cooperative agreements.

February 1997

- Develope baseline agency surveys.
- Developed sampling strategy to target agencies in the tri-county area that serve HIV seropositive individuals.

March 1997

- Administrative meetings with potential network agencies to develop scope of services.
- Potential agencies for out-stationed staff identified.
- Continue development of baseline agency surveys.

April 1997

- Staff training for baseline agencies.

- Interviews conducted.
- Scope of mobile team activities defined.

May 1997

- Baseline agency surveys conducted.
- Advertise of mobile team services.

June 1997

- Agency survey database established.
- Cooperative agreement content finalized.

July 1997

- Initial requests for training and client consultations fulfilled.
- Agency surveys completed.
- Program coordinator leaves and is replaced.

August 1997

- Data entry and cleaning for agency surveys begins.
- Provider surveys developed.

September 1997

- Hire of mobile team member.
- Begin outstationed positions with the King County Correctional Facility, the Lyon Building and NorthWest Family Center.

October 1997

- CA requires agency-specific language.
- Mail provider surveys.
- Client consultation and training database established.

November 1997

- Develop strategies to obtain consumer-level information in geographical domain of project.
- State Medicaid database for HIV seropositive individuals no longer available.
- First issue of newsletter distributed.

January 1998

- Evaluator resigns and is replaced.
- Advertising strategies developed.
- Content and format of newsletter established.
- Group at Stonewall Recovery Center established.
- Three trainings held and 37 client consultations provided from June - Jan 1998.

March 1998

- Obtain Ryan White consumer data for three counties.

May 1998

- Second group at Stonewall Recovery Center begins.

- Client, provider, and general brochures developed.
- Recognize need for website.

June 1998

- Address objections to provider and agency surveys.
- Negotiations to obtain King County case management database begin.
- Minimal use of outstationed staff at Lyon Building reported.

August 1998

- Cooperative agreement with King County Jail approved by Dept. of Public Health, UW School of Medicine and Dept. of Psychiatry and Assistant Attorney General' s office and the University of Washington.

September 1998

- Senior evaluator resigns and is replaced.
- 85 HIV seropositive clients served; 18 trainings held.
- Outstationing at Lyon Building discontinued. Consultation available by request.

October 1998

- Need for chemical dependency expert on mobile team recognized.

December 1998

- Identify and formalize relationship with Snohomish Health District: outstationed psychiatrist.

January 1999

- Hire chemical dependency expert.

February 1999

- 20 client consultations provided; 15 trainings with 331 participants.
- Mid-project agency surveys revised to decrease length.

March 1999

- Revised methodology for mid-project agency surveys. Network agencies interviewed and non-network agencies receive mail-out survey.

April 1999

- Discussions begin with King County Jail on findings from clients seen.
- Focus at all network agencies shifting to continuity of services when project complete.
- Receive King County case management database.

July 1999

- Sixty-five clients served; 31 trainings with 989 participants provided.
- Seattle Needle Exchange identified as possible location for outstationed chemical dependency expert.

September 1999

- Negotiations for cooperative agreement with Seattle Needle Exchange begin.
- No longer able to fulfill all requests for training due to geographical restrictions, focus and/or financial resources.
- Agency-level data entered and cleaned.

November 1999

- Strategy developed concerning advertising the last year of the mobile team.
- Final report available on King County case management database.

January 2000

- Agency-level data analyzed.

February 2000

- 37 clients served; 18 trainings provided.

April 2000

- Production of video "Dangerous Combinations: HIV Medications and Street Drugs" completed.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Tri-County Collaberation service model please contact:

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The Harbor Project, University of California, Los Angeles

Facilitating Workforce Entry

Authors: David Martin, Paul Arns and Stephanie Kim

Introduction

Thanks to dramatic advances in the treatment of HIV, individuals living with the disease are now more able and interested in returning to the workforce. But re-entry into the working world is not as simple as it might seem. For example, many people who left their former jobs because of their illness are ambivalent about returning to the same place of employment. Sometimes the battle with HIV has changed life goals such that indeviduals wish to follow a different course – for some this might mean a life of activism and for others it might mean a desire to find more meaningful work. Some people with HIV are facing an end to government benefits and are out in the workforce for the first time. As those with HIV/AIDS look forward to longer and healthier lives, a vital component of comprehensive care is the return to work. Employment is a crucial part of mental health, self-esteem, and survival. But the HIV diagnosis is often one of the smallest barriers a person faces in the re-entry process. More pressing needs such as education, housing and child-care can greatly hinder the return to employment.

The Harbor-UCLA vocational/rehabilitation/workforce entry program assists unemployed/disabled people with HIV/AIDS in their efforts to reenter the workforce. Among the HIV positive patients seen at the Harbor UCLA Medical Center and the Long Beach Comprehensive Health Center's HIV clinic, a large percentage reported being unemployed, and many reported a need for assistance in their efforts to return to work. At the Long Beach Comprehensive Health Center, a majority of the HIV patients were able to work but needed assistance in workforce entry. Employment efforts are often impeded by intervening factors such as substance

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abuse. Those facing continued unemployment are more likely to drop out of medical care, increasing the chances of relapse or continued substance abuse.

As those with HIV/AIDS look forward to longer and healthier lives, a vital component of comprehensive care is the return to work.

Employment is a crucial part of mental health, self-esteem, and survival.

Location

The program operates primarily in Long Beach, California. Long Beach has the second highest municipal incidence of reported AIDS cases in California and is in the southern region of Los Angeles County. Most individuals participating in the program live in Long Beach.

Services

Clients entering the program receive a complete mental health, psychosocial, neuropsychological, and vocational interest and skills confidence assessment. Following completion of the assessment, clients meet with a psychologist to discuss the results and their potential employment goals. Following this meeting, clients meet with their project case managers to finalize their goals and to develop implementation plans. Education and job placement needs are addressed through referral to the Long Beach Career Transition Center. Other needs such as substance abuse or mental health treatment also are addressed through referrals to local HIV mental health and substance abuse treatment programs. Each plan is designed to integrate medical, mental health, psychosocial, vocational and education services.

Lessons Learned

Lesson #1: Create linkages.

As the needs of those with HIV/AIDS change and become more specialized, the range of services necessary for comprehensive treatment often exceed the resources of a single agency. Providers are encouraged to remedy this problem by linking with other facilities through formalized agreements or other such strategies.

When the Harbor Program identified that vocational/rehabilitative training was a critical and unmet need, the agency faced the dilemma of whether to provide the services on-site or develop formalized linkages with other agencies. After an assessment of agency experience and economic feasibility, program staff decided to contract out for these services. The program's lack of expertise in the areas of vocational rehabilitation, job training, and job development would have created significant obstacles for Harbor, such as the hiring of appropriate staff, the development of new timelines for project implementation and the creation of new networks for job placement.

Linking with other facilities can be achieved in several ways. Some partnerships can be new and will require significant resources, while others can be built on existing relationships in the community. Since relationship building requires time and resources, it is best to begin the process by taking advantage of prior relationships.

Lesson #2: The importance of building upon informal prior relationships.

Having personnel who are well known in the community greatly facilitates linkage development. Often staff member and administrators have extensive personal connections and relationships in the work field and with specific staff at different community organizations. It is these informal personal relationships that lay a foundation for successful linkage, however, the opposite case might also hold true – key agency staff might have strained relationships with staff at other agencies, making it more difficult to create linkages.

The Harbor Program was able to take advantage of prior positive relationships. The project director was the key individual/network builder for the project. Since the 1980's he had formed and nurtured many community relationships through his involvement in different research projects and service delivery programs in the area. His research as well as his representation on committees such as the Long Beach HIV Care Consortium fostered numerous and regular interactions with key individuals in the Long Beach Department of Health and Human Services, all who were key to forming the necessary linkages.

One of Harbor's main partners in the provision of vocational rehabilitation services, Goodwill Industries (a vocational training agency), was secured through such existing relationships. Goodwill Industries of Long Beach and South Bay has a strong reputation for successful job assessment and retraining programs for the deaf, the mentally and physically challenged people. The initial relationship with Goodwill Industries was formed following an informal discussion between Harbor's project director and the development director at Goodwill Industries

Early efforts to develop this agreement between the two agencies transpired smoothly due to this personal connection. However during the drafting of the proposal and in the contract negotiations, different personnel became involved. These staff members were not familiar with or involved in the decision making of the linkage agreement process between Harbor and Goodwill. As a result, several meetings took place to acquaint Goodwill staff with Harbor's program goals. Three months after award of the contract, staff turnover at Goodwill hindered the smooth functioning of the proposed linkage, which ultimately might have added to the lack of successful referrals to Goodwill.

> ...informal personal relationship(s) lay a foundation for successful linkage, however, the opposite case might also hold true —key agency staff might have strained relationships with staff at other agencies, making it more difficult to create linkages.

Personal trust in the linking agency as well as knowledge of the proposed linkage serves as an important basis for which linkages can be built. If that trust does not exist prior to the linkage, the program should plan activities that would engender trust, communication and knowledge sharing between the two agencies. But efforts to better acquaint and familiarize staff at the linking agency after a linkage has been created do not necessarily guarantee the success of a linkage. Staff responsible for implementing the linkage or making the necessary referrals between agencies have to not only be knowledgeable about the proposed linkage, but they also must be convinced and committed to the new interorganizational relationship. Engaging key staff in the decision-making related to that relationship can enhance the commitment of staff. Even though staff turnover might complicate participation in the decision-making process, any such efforts can make a difference.

Lesson #3: Ensure an appropriate match between clients' needs and services offered.
The Harbor program based initial estimates of service need on feedback from agencies in the Long Beach HIV care consortium. This information suggested that Goodwill would be a good match in the provision of job training and vocational rehabilitation services.

But the services Goodwill provided were later determined to be a poor match for Harbor clients for several reasons. Three factors emerged to conspire against a successful collaboration. First, the clients Goodwill

Industries had historically served (e.g. mentally retarded, severely mentally ill, deaf) differed substantially from the individuals who enrolled in the Harbor program. In contrast to Goodwill's traditional clients, the project's client base included a mix of people ranging from previously high functioning professionals to those with little or no previous gainful employment, alcohol and drug use histories, and personality disorders. Despite whatever obstacles to employment they might have experienced, most of these clients' historical level of functioning was higher than that of most clients served by Goodwill.

A second factor that hindered success in this linkage was the limited number of rehabilitative services Goodwill offered. Whereas the Long Beach Career Transition Center was able to provide a broad range of training through the use of subcontracts with various trade and technical schools (as well as with the Long Beach Unified School District and Long Beach City College), Goodwill Industries provided all programming on-site. Training was limited to basic skills in computer keyboarding, computer data entry, retailing, and sheltered workshops. This limited scope of training made matching with most of the project's clients need very difficult.

Finally, the Harbor program met with considerable client resistance to training with Goodwill because of its reputation as an agency that provides services to certain marginalized groups. Although Harbor's population is also marginalized, the nature of its stigma is quite different from the stigma associated with Goodwill's clients. Stigmatized groups can be just as (or more) stigmatizing of other disenfranchised groups as the general public, and sensitivity to this possibility is important.

> Three factors emerged to conspire against a successful collaboration. First, the clients differed substantially... second, was the limited number of rehabilitative services ...third, the Harbor program met with considerable client resistance to training with one of the contractors.

Lesson #4: If client need is not met, pursue other options.

Harbor discovered partway into the first year of the project that Goodwill Industries was not being utilized as fully as had been initially anticipated. Because the program was still new, and because Goodwill had requested that agencies not send their "problem clients" initially, it was anticipated that as time went on the program would use Goodwill Industries with greater frequency. But initial expectations concerning use of Goodwill Industries were higher than the actual use in both the first and second years of the project.

The Harbor program's use of the Career Transition Center was substantially higher than the use of Goodwill Industries, so Harbor's agreement with both agencies was altered to reflect a primary subcontract with the Career Transition Center. This arrangement provided for greater flexibility and responsiveness to changes in the service needs of clients entering the program, and required only one contract for the services provided through the Career Transition Center and Goodwill Industries. It also allowed Goodwill Industries to be viewed in the overall program in a similar fashion as other private training institutions that contract with the Career Transition Center to provide employment training. The Harbor Project's ability to modify programs to meet changing client needs has proven to be important in providing the best and most comprehensive services.

It is vital that projects continually assess or be aware of the changing needs of the target population and make attempts to ensure the needs of their clients are being met by the appropriate providers. Many times, the services that are planned and implemented are not suited to the proposed population. Clients possess particular characteristics which necessitate very specific services or that services be delivered in a specific environment. Service needs can change during the course of the project, so providers must assess and be able to modify programs to meet clients' changing needs.

The Harbor program staff realized the importance of this flexibility. After the first year of Harbor's services, the AIDS Project/Los Angeles conducted a focus group study that noted areas of need among persons with HIV. This study confirmed the need for vocational and rehabilitative services for those with HIV but did not specify a mechanism for the provision of such services. Harbor program staff has had to continually assess both the target population's needs and the most effective way to meet these needs. It is also important for all agency staff involved in the project to be aware of the target population's unique characteristics and needs and the interaction of these two factors. For example, it was discovered that those in the vocational/ rehabilitative fields were not knowledgeable about relevant HIV issues as their area of work mainly focuses on securing benefits for clients. Ad hoc training on HIV issues was provided to staff at cooperating agencies. However the program might have benefited from more formalized cross training between the different agencies.

Lesson #5: Build community support.

It is essential for a project to be aware of the community's attitude towards the target population. For example, Harbor first assessed the community's response to the program and possible obstacles clients might encounter in finding work. After doing so, the project approached the Greater Long Beach Area Chamber of Commerce and nominated a Chamber representative to Harbor's advisory committee. This representative assisted in developing and distributing a mailer to 300 Chamber members to recruit focus group participants as a first step in gauging local business response to the needs of people with HIV. Although only a few members responded, the project was able to obtain valuable information. HIV-employment issues might not represent a priority for many potential employers. The employers in the focus group were concerned with issues ranging from health insurance to maintenance of confidentiality for individuals who have to take off a lot of time for doctor's appointments. Having community support and knowing what community obstacles the project has to confront in providing services greatly enhances the agency's ability to deliver services and form linkages.

Summary

Prior to implementation of the Harbor program, referrals to the State of California Department of Rehabilitation were frustrated by order of selection (a tool used to determine service eligibility), poor funding for the department, and lack of staff responsiveness and knowledge. In particular, in times of especially low funding the order of selection was used to restrict service to those who were most severely disabled, which often did not include people with HIV/AIDS.

The Harbor program has been able to demonstrate the need for rehabilitative services for people with HIV/ AIDS, as well as the feasibility of undertaking these services. As a result, the local office of the Department of Rehabilitation has agreed to take referrals from the community, and agreed to partner on a major application for a research project investigating the relative effectiveness of two approaches to vocational rehabilitation for people with HIV.

The Harbor Project Chronology

July – December 1995

- Long Beach HIV Care Consortium conducts local needs assessment and identifies vocational rehabilitation/job placement services as an emerging need among people with HIV/AIDS.

December 1995

- Local discussion group convenes to explore options for development of vocational rehabilitation/ workforce entry resources for people with HIV. Group meets monthly.

March – May 1996

- Following consultation with discussion group, application to HRSA developed. The application includes specific vocational rehabilitation needs assessment that incorporate re-analysis of local community needs assessment data, survey of case-management providers, and analysis of data from two local clinics.

September 1996

- HRSA announces award.

October 1996

- Project developed and program procedures refined.
- Personnel recruitment begins.

December 1996

- Hire program coordinator, psychologist, and social worker.

January 1997

- Coordination meetings with AIDS Project Long Beach, AIDS Project Los Angeles.
- First participant intake interview, testing, and SCID interview.
- Monthly area case managers meeting.
- Press release issued.
- Newspaper article appears in the *South Bay Daily Breeze*.
- Newspaper article appears in the *Press-Telegram*.

February 1997

- Item about the project appears in *UCLA Today*.
- Rehabilitation director at Goodwill Industries resigns.

March 1997

- First participant consultation with psychologist.
- First referral to Career Transition Center for vocational training.

April 1997

- Hire replacement program coordinator.
- Coordination meeting with Career Transition Center.
- First referral to Goodwill industries for vocational training.

May 1997

- First part-time job placement.
- First full-time job placement (food service).

July 1997

- New brochure developed and distributed to HIV clinics and case management programs.
- Newspaper article appears in the *South Bay Daily Breeze*.
- First self-employed participant.

August 1997

- Forms developed for follow-up interviews.
- First temporary job placement.

- First meeting of project advisory group, which includes representative from the Greater Long Beach Area Chamber of Commerce.

September 1997

- Article appears in the *Orange County Blade*.
- Quarterly advisory group meeting with representatives from local businesses, case management organizations, vocational rehabilitation centers, health and mental health care providers.
- 100th participant begins program.

October 1997

- First six-month follow-up interview completed.

November 1997

- First interview for comparison group completed.

March 1998

- 50th participant completes testing and is referred for vocational placement or training.
- First placement in civil service.
- First participant enrolls in internship through Career Transition Center

April 1998

- Focus group of Greater Long Beach Area Chamber of Commerce members conducted.

October 1998

- Contracting arrangement with Goodwill Industries terminated.

March 1999

- 100th participant completed testing and is referred for vocational training or placement.
- First participant completes 2 year follow-up, he is working full-time.

April 1999

- 200th participant begins program.

October 1999

- 236th and final participant begins program.

March – April 2000

- Department of Rehabilitation agrees to accept referrals and to partner in new proposal to NIMH.

Further Information and Technical Assistance

If you are interested in obtaining further information about the developed by the Harbor Project and the service model please contact:

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North Carolina SPNS Integration Project, Duke University

An Integrated Service Delivery System for Rural People Living with HIV/AIDS

Authors: Kate Whetten-Goldstein, Trang Nguyen and Stephanie Kim

This article highlights some of the lessons learned from the North Carolina SPNS Integration Project (NC SIP). It is based on a four-year intervention.

Introduction

Current systems for providing health and social services are fragmented for individuals with HIV living in rural areas. No adequate model of care has yet been developed for these rural areas where the spread of AIDS is occurring at the fastest rate. NC SIP is forming an integrated delivery system (IDS) across 54 counties of eastern North Carolina to improve the coordination of comprehensive medical and social services for underserved rural persons with HIV/AIDS.

The Integrated Delivery System

Model of care

The combination of components that compose the Integrated Delivery System are what truly make NC SIP unique in its intervention. These components include: formal and informal communication among HIV providers (e.g. meetings, trainings, telephone calls, newsletters, web site); agency coordinators continuously facilitating the working relationships and communication of HIV providers; a computer network to assist HIV providers in tracking all health and social services; and clinical and ambulatory care mapping. More about the specifics of each component will be discussed later in this document.

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Services

The intervention does not provide direct client services. Medical and social services are funded through other sources. Through multiple strategies, such as a computer network and agency coordinators (these will be outlined later) NC SIP focuses on developing an integrated delivery system to enhance provider communication and coordination for the care of HIV-positive people.

Partner Agencies

Three Infectious Diseases (ID) Clinics of Duke University Medical Center, University of North Carolina-Chapel Hill and East Carolina University School of Medicine, HIV case management agencies, Ryan White CARE consortia, the AIDS Care Unit within the NC Department of Health and Human Services, NC prison systems and other community-based AIDS service organizations form the Integrated Delivery Systems in 54 counties through-out eastern North Carolina.

Lessons Learned

The success of NC SIP is attributed to a mélange of linkage strategies. In implementing the intervention, the project had to modify these linkages to make them more suitable to participating agencies' needs. Each linking strategy chosen offers a way to bring together agencies and organizations that are not close geographically or personally. These linking strategies form the necessary infrastructure/foundation for communication across different providers to ensure quality care.

Lesson #1: Agency coordinators are the glue that holds the system together.

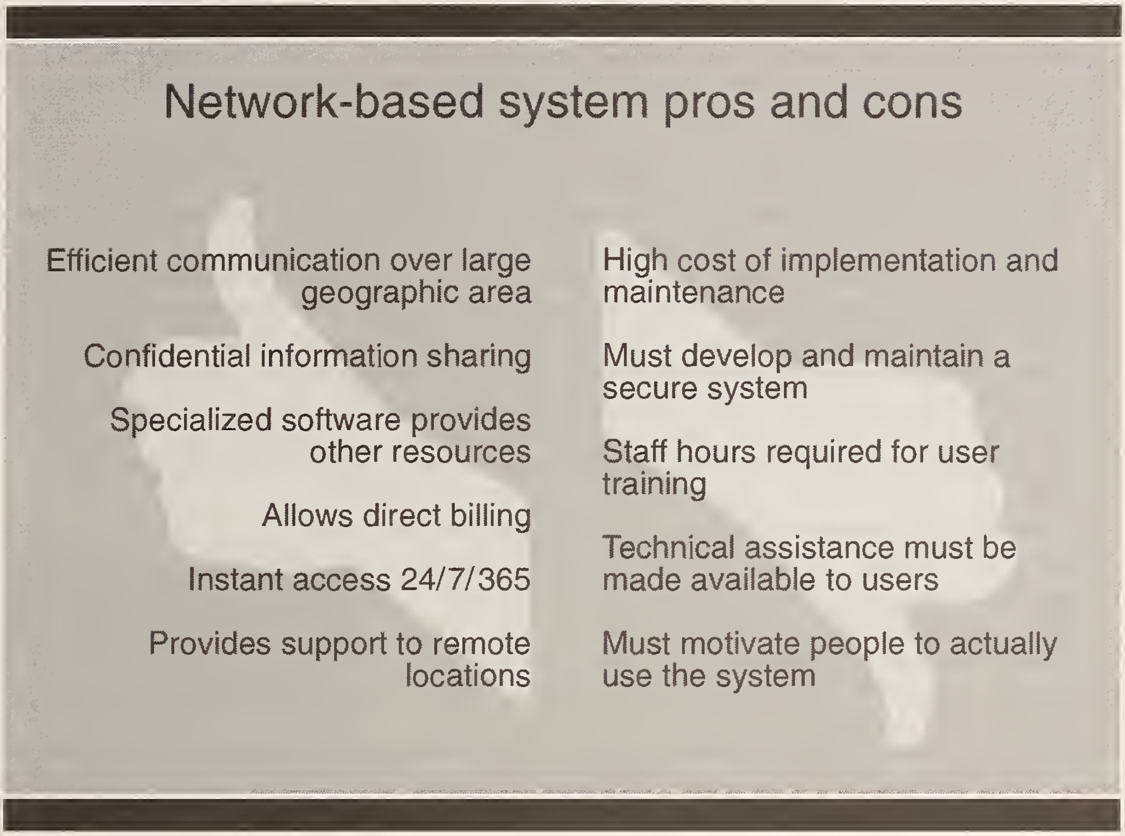
Agency coordinators are a critical link in NC SIP efforts to create an integrated system of care. Three agency coordinators are involved in rolling-out and stabilizing Provide, the computer network software, via group and individual trainings and monitoring. Coordinators conduct HIV-related training workshops (i.e., substance abuse, grief/dying); organize regular regional provider meetings; serve as liaisons for case managers, consortia directors and ID clinicians; help address client concerns and needs in providing appropriate care (i.e., creating Provide billing functions, prepare HIV informational fact sheets); and ensure that all who provide HIV-related care are educated about other HIV-related providers in their area. In short, agency coordinators provide local technical assistance in all matters ranging from Provide to issue-specific training workshops. In these ways, HIV providers are the agency coordinators' clients.

> Computer net users must trust the confidentiality of the system or they will not use it.

The agency coordinators have worked hard to build and maintain the providers' trust in the project's purpose and work. NC SIP has been fortunate in hiring agency coordinators whose past ties in the HIV community crossed over into their work with NC SIP. They built upon this trust and helped agencies see the utility of Provide and of coordinating efforts with other providers to benefit clients. Providers have learned they can contact the agency coordinators easily via telephone, fax or email, which further enhances trust. The agency coordinators also often travel to meet with providers individually and for group meetings/trainings. They have coordinated two case managers' conferences, which addressed training in an open and supportive environment. The frequent contact with and attention from the agency coordinators allow providers a sense of support from a working environment in which they often do not feel support.

Lesson #2: The computer makes distance managable.

To develop an IDS that spans this large rural area is a challenge in itself. To overcome difficulties in communicating over a large rural area, the project chose to establish a computer network as the main feature of the IDS because of its ability to allow efficient and confidential information sharing and communication over great distances. Additionally, the computer network, based on the software Provide, serves multiple other purposes. It contains resource pages that provide information on such topics as



Network-based system pros and cons

- Efficient communication over large geographic area
- Confidential information sharing
- Specialized software provides other resources
- Allows direct billing
- Instant access 24/7/365
- Provides support to remote locations

- High cost of implementation and maintenance
- Must develop and maintain a secure system
- Staff hours required for user training
- Technical assistance must be made available to users
- Must motivate people to actually use the system

Medicaid and ADAP eligibility. A billing template was created for agencies to bill the consortia directly for services; this form was designed in direct response to requests from case managers who wanted to utilize the computer system more efficiently. Another important advantage of the computer network is its ability to accommodate varying schedules and personalities of the groups involved (physicians seeing clients and case managers in the field). Providers are able to receive and respond to questions and information in a timely manner. The system also has a discussion page used primarily by the case managers to pose and respond to questions regarding client care. This information exchange functions as a support network for individuals doing similar work who otherwise would be isolated.

There are also disadvantages to the computer network which include the cost to create and maintain a secure network, and necessary training, and technical assistance to get users onto the system. This assumes agency staff will want to use the system. That is not always the case. Users must trust the confidentiality of the system and feel it meets their needs.

Lesson #3: Caremaps are an effective way to get everyone on the same page.

Another strategy that NC SIP utilizes in developing the Integrated Delivery System is caremaps, which are standards of care for providers of people living with HIV/AIDS. The purposes of the caremaps are to: (1) standardize care between different sites; (2) facilitate communication concerning goals and means to achieve the goals of the different components of the health care and social services system; and (3) provide educational material for the physicians-in-training and rural physicians who have less exposure to HIV/AIDS. Caremaps outline recommendations for the care of persons with HIV/AIDS: their use should be tempered with good clinical judgement that takes into account individual needs of the patient.

While the caremaps were not originally proposed to address issues of integration, they have in fact become a means by which providers come together as well as communicate with each other. Each caremap has been distributed to more than 600 providers in North Carolina and nationwide during conferences. The opportunity has enabled providers to learn about concerns faced by counterparts in different areas of the state, which facilitates cooperation. Distribution of the caremaps has enhanced integration efforts by educating providers across eastern North Carolina about: (1) standards of care and; (2) the work of NC SIP. The caremaps help providers understand the overall goal of NC SIP from a perspective different than the computer system or trainings.

Lesson #4: NC SIP Philosophy 101—all parties must buy-in.

NC SIP needed to invest much effort in convincing different groups (ID clinics, case managers, AIDS Care Unit, consortia) to join the collaborative initiative. While a variety of providers and administrators at all levels of HIV care were involved in the preparation of the proposal, when grant funding was awarded, different providers were in place and others who had not been directly involved were threatened by the potential of the grant. Persuasion involved developing trust. Trust building efforts consisted of face-to-face meetings in which an open process was emphasized and the goals, opinions and missions of participating agencies were respected. NC SIP worked to create an open process by which all providers, regardless of title and position, had equal opportunity to participate in the discussion to develop an integrated model of care. It was this process that best facilitated the development of the IDS.

Initial efforts were critical due to NC SIP's position in the state. NC SIP is its own entity and does not provide direct client services nor does it have any financial obligation to providers or clients. Therefore, NC SIP's success is based on the willingness of providers to volunteer their time and resources to create the infrastructure needed for integrated care. This structure encourages flexibility and allows for greater responsiveness than is seen in other organizations. As an example, the original proposed intervention did not include a computer network as the primary focus of the IDS. The idea for the network was born out of meetings of case managers and ID clinicians. It was through these open meetings that NC SIP staff realized potential difficulties and problems with the original proposed intervention. It became essential to make changes to the intervention to address conflicts.

Building trust requires face-to-face meetings in which the goals of network partners are openly discussed.

NC SIP had originally proposed to create a system by which case managers would be linked to the ID clinics via a "super case manager" who would work out of the ID clinics and act as a link between the ID clinics and the case managers. After the proposal was funded and presented to consortia administrators, the state-level AIDS Care Unit and case managers, providers were outraged that (1) they were not all included in the preparation of the proposal (the AIDS Care Unit had been involved, but not other providers); (2) that the proposed model was hierarchical in nature with the ID clinics holding the top rank and required case managers to report to yet another entity. NC SIP brought together the ID clinicians, case managers and consortia directors to discuss an alternative. The group developed the idea for a computer network to facilitate the transfer of information regarding clients.

By addressing their needs and incorporating a computer network into the overall structure of IDS, providers saw NC SIP as an entity that listened to their needs and made their ideas a reality. In this way, the NC SIP team was seen as a liaison for and supporter of community and medical providers, thereby aiding the implementation and regular use of the computer system. Since NC SIP could not enforce agencies' computer usage, one may think it difficult to build an IDS based on a computer network. However, since participation was voluntary, IDS devoted much time to listening, involving, persuading, and bringing on board staff at the difference agencies. As a result, the agencies that agreed to use the system were excited and were convinced of its advantages.

This relationship building also was crucial in dispelling preconceived distrustful or negative stereotypes that might have resulted in complications with the implementation of the computer network. The groups of agencies that NC SIP is trying to integrate are represented by many different professions with varying perspectives and opinions. For example, case managers had previously reported negative experiences with the ID clinics of the academic medical centers. ID clinicians would not respond to questions regarding client visits and would not provide essential information such as an HIV diagnosis necessary to meet Medicaid eligibility. Case managers said physicians would not respond to their telephone calls and were sometimes rude when they did respond. ID physicians and social workers reported case managers also would not return telephone calls and often did not provide adequate case management services they believed to be integral to client care. In addition, consortia administrators and case managers were distrustful of an academic medical center leading the integration of care. They were convinced the academic medical centers would want to buy the case management agencies or create capitated payment rates that would benefit the centers. They felt that academic medical centers were out of touch with the realities of working with HIV positive clients on a day-to-day basis, and were not capable of putting together a network that would benefit client care.

By involving all participating parties in the development of the intervention through open meetings, the different groups who were thought to differ drastically in professional views and their standards of care were able to work past their distrust of and negative experience with each other by focusing on the common goal of providing the best and most comprehensive and continuous care for these rural clients. Additionally, they were able to make modifications to the intervention to take into account their needs. It is the belief of NC SIP that a computer network would not have succeeded had case managers and ID clinic staff not given critical input in the final design of the Integrated Delivery System computer network.

Lesson #5: NC SIP Philosophy 201—flexibility is required.

From the very beginning, the need for the NC SIP team to be flexible in its efforts and vision has been integral to the success of the project. As exemplified in the creation of the clinical database within Provide, NC SIP had to constantly address the multiplicity of providers and their interests. The initial Provide package contained the care management database, which enabled case managers to electronically maintain records and communicate with the ID clinics, but the ID clinicians did not see Provide as useful on a daily basis. Therefore, in order for the ID clinics to utilize Provide regularly, it was necessary to create a database that they too could use to maintain records electronically. With the creation of the clinical database, ID clinics are using Provide on a regular basis and communicating with case managers to coordinate care by sharing client information as needed.

Lesson #6: The sky's the limit.

All the initial efforts spent on convincing partners of advantages of using the computer network as well as making them feel that they were full and active participants of the system paid off in terms of NC SIPS's success. Many of the ID clinics are convinced that the computer network is an effective way to provide the most coordinated care. This had led ID clinics to fund, on their own, the renewal of the software for the computer network. Part of this success was contingent on the efforts made in the beginning to make participants feel they were active in the decision-making process. Providers who were able to experience the advantages of the computer network are most likely to discuss the advantages of the network with colleagues, which will facilitate growth of the network. Additionally, institutional norms have been altered which allow for the possibility of the network to be continued with or without funding after the project.

NC SIP Project Chronology

April 1996

- Academic medical centers begin speaking with each other through the investigators.
- The North Carolina AIDS Care Branch assists in the editing of the proposal.

August 1996

- HRSA expresses interest in proposal but the budget must be cut in half. A new survey firm is found and resources for the entire project are cut.

October 1996

- Negotiations with direct care providers.

January 1997

- Collaborating agencies meet and commit to the project.
- Creation of caremaps.

April 1997

- NC SIP commits to finding computer system and funding.

June 1997

- Four research assistants work full-time on the research arm of the project. Clients from Infectious Diseases clinics consent to participate in research.

August 1997

- Agency coordinators and demonstration team hired.

October 1997

- HRSA provides additional funding to assist with computer network proposal.
- NC SIP raises $55,000 from pharmaceutical companies to purchase laptop computers.
- Computer administrator hired.

January 1998

- 37 agencies linked via computer and 62 individuals become users.
- Computer network training begins.

February 1998

- Agency participants meet to review and update software fields.

June 1998

- Case managers surveyed regarding substantive training needs.
- Team members meet with NC home health and hospice to assess the possibility of creating joint caremaps.
- Project staff and survey firm begins the work of refining the survey data.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by NC SIP, you are welcome to contact the project director and request technical assistance:

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The Whole Life Project, University of Miami Department of Psychiatry

Integrating Services for Poor Women of Color

Authors: Sally Dodds and Angela Aidala

Introduction

Poor women of color who are disproportionately both infected and affected by HIV/AIDS, face multiple mental health and psychological burdens that complicate effective delivery of health care resulting in their poorer prognosis. Mental health problems constitute an unmet service need for HIV-infected women and children. Many primary care providers do not integrate specialized services into medical treatment, which creates a barrier to the treatment of mental health problems. As a result, such problems often go undetected and untreated. This could contribute to increased distress, lack of access to early intervention services and prevention of perinatal HIV transmission through zidovudine treatment, non-access to clinical trials, and ineffective health behaviors including poor adherence to combination HIV therapies.

Medical and social service systems with access to mental health and substance abuse treatment services provided typically through referral mechanisms are the primary care providers for people with HIV. These structures tend to fragment comprehensive and coordinated service delivery and thus create significant barriers to care. For HIV-infected women and their children, these dominant models are not broad enough to include the variety of services and providers necessarily intertwined in the overlap of health, mental health, substance abuse, violence, and psychosocial stressor needs of this highly vulnerable population.

A more appropriate model of care is an integrated service system. Integrated systems are, necessarily, comprehensive approaches to service provision for consumers with complex needs. A general definition of services integration is wherein two or more entities develop formal linkages for the purpose of improving

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outcomes for constituent clients. Integrated services are different from categorical programs that typically have unique funding and eligibility requirements for specific services offered to discrete target populations. Such non-integrated services are considered to be duplicative, fragmented, inefficient, costly, and often not in the best interests of the consumer. In contrast, integrated services are seen to have the ability to serve multi-problem patients in a comprehensive manner, provide greater service accessibility and continuity of care, achieve early intervention and prevention, and reduce duplication, inefficiency, and costs.

Whole Life integrates mental health services into a “one-stop” program for women and children in HIV primary care (including obstetrical care). Goals of the project are to:

- train existing personnel (primary care, psychosocial providers, and case managers) to detect and manage mental health problems.

- deliver mental health services in, or linked to, HIV primary care settings.

- increase patient access to, and utilization of, mental health, substance abuse, and trauma services.

- improve mental and physical health outcomes for women and children who receive services.

Location

The Whole Life Services Integration Project serves HIV-infected pregnant and non pregnant women, their children and care-giving family members who receive primary care through the HIV clinics of the Departments of Obstetrics and Gynecology and Pediatrics at the University of Miami School of Medicine/ Jackson Memorial Hospital.

Miami (Miami-Dade County) is an important geographic site to develop integrated service delivery systems for HIV infected women and their children. Through June 30, 1997, Miami reported 19,205 cumulative cases of AIDS, and its annual rate of AIDS cases (86.6/100,000) represents the third highest rate among major metropolitan cities in the United States. Women, particularly minority women, represent an increasing proportion of AIDS cases in Miami. Women now comprise 35 percent of the total number of new HIV infections in Miami. Black women (including African American and Caribbean) represent 77 percent of these cases. One-third of women (32.8 percent) reported IV drug use as their route of HIV transmission, while another third (33.7 percent) reported heterosexual contact with a male partner with high HIV risk (e.g., an injecting drug user or a man who had sex with a man). Women between the ages of 20-49 comprised the highest rate of cumulative AIDS among adult/adolescent women in Miami at 89 percent.

Service Need

Preliminary analyses of 172 Whole Life patients reveal that they are low income (95 percent have individual incomes of less than $999 per month), single (55 percent), and are of minority backgrounds (greater than 90 percent). Fifty nine percent have an 11th grade education or less. A third of the patients first learned that they were HIV positive at the time of a prenatal visit. Rates of substance use are high; however, heterosexual transmission is the highest viral risk exposure category.

Of particular importance to the project is the prevalence of mental health problems in the women served, and predictive measures indicate that rates of these problems are quite high. Nearly 30 percent of women screened using a standardized assessment tool exceeded established cut points for depression; 13 percent were diagnosed as having a major depressive disorder by a mental health clinician.

Nearly 60 percent of all women screened report having experienced some degree of physical and/or sexual abuse in their life times (defined as childhood physical abuse, childhood sexual abuse, rape, or recent/current domestic violence). The experience of traumatic events infers a high prevalence of anxiety disorders, including panic attacks, generalized anxiety disorder, and post traumatic stress disorder — areas on which the program will be conducting further analyses. Very few of the women report receiving any type of mental health service outside of those offered by the Whole Life program. Thus, in addition to primary health services, women also need access to entitlement benefits and concrete services for unmet basic human needs, psychosocial counseling, mental health services, substance abuse treatment, and protective intervention from violence or abuse. For those women who are pregnant and/or parenting, the need for services increases.

What is the need?

Among the 172 women that Whole Life serves:

✖ all low income - 95% with less than $999 per month

✖ 55% single

✖ most from minority backgrounds - greater than 90%

✖ 59% with an 11th grade education or less

✖ 30% with depression

✖ 13% with a major depressive disorder

✖ 60% experienced physical and/or sexual abuse (defined as: childhood physical abuse, childhood sexual abuse, rape, recent/current domestic violence)

A Theoretically Derived Model for Clinical Care and Outcomes Assessment

A fully integrated system is comprehensive in scope, operates collectively, fully blends activities, demonstrates transparent lines across service categories, and is multi-purpose and cross-cutting. Patient problems are treated as a whole, and individuals are treated as part of family and community systems. Whole Life utilizes a theoretically derived clinical service model that integrates multiple services for pregnant and non-pregnant women who are HIV positive through interview assessment and the creation of a personal care team. Systematic assessment provides data for both clinical care and patient outcome research within the constraints of a clinical setting.

Whole Life is a woman-centered, family-focused, and culturally-competent "one-stop" program that integrates mental health and substance abuse treatment services with primary HIV medical care (for women and children), obstetrical and gynecological care, and a range of supportive case management and social services. Whole Life collaborators include: the University of Miami School of Medicine Departments of Psychiatry, Obstetrics & Gynecology, and Pediatrics; the UM Center for Family Studies; the inpatient Maternal Addiction Unit of Jackson Memorial Medical Center (JMMC); and, Barry University School of Social Work. Whole Life Network is thus defined as being a system of comprehensive care that is based on formal collaborative agreements among service provider agencies/institutions.

Provider Team

To provide the necessary range of mental health services in the Whole Life model, Whole Life supports a dedicated mental health team (a psychiatrist, a psychiatric nurse practitioner, a clinical psychologist, and a clinical social worker) that works on site in the primary care clinics, side-by-side with the primary care providers. The OB/GYN case managers and social workers conduct routine screenings for major mental health problems on all women in the primary care clinics (i.e., for depression, anxiety, post traumatic stress disorder, substance abuse, and thought disorder). When the routine screening indicates a potential problem requiring additional assessment, the OB/GYN social workers, in conjunction with the Whole Life mental health team, conduct more in-depth mental health assessments and psychiatric evaluations. When indicated, psychotropic medications are proscribed, with co-monitoring by the psychiatrist, psychiatric nurse practitioner, and OB/GYN primary care provider. Individual, group, and family therapies are provided by the blended team of the Whole Life clinicians and the OB/GYN social workers. On occasion when inpatient hospitalization is required (either for medical, obstetrical, or psychiatric reasons), the blended team continues to provide services in the inpatient unit.

In OB/GYN, primary care services are provided by advanced registered nurse practitioners (ARNPs) with attending faculty physician back-up; in Pediatrics, these services are provided by pediatric immunologists. In both programs, each patient/family is assigned both a social worker to provide crisis intervention, individual and group counseling services, and a case manager to coordinate service and benefits resources. Social workers and case managers are matched to patients according to language and cultural similarity. The cultural/lingual sensitivity and capacity of the Whole Life project is especially relevant in a environment such as Miami-Dade County, with its multiple ethnicities and languages.

Lessons Learned

Following are some important lessons learned by the Whole Life project staff as a result of their experience integrating mental health and psychosocial services, and systematic patient outcome research, in a busy primary care setting.

> Involve individuals at the highest organizational levels possible since without their committment....neither structure nor culture will change.

Four groups of variables are identified as influential in establishing service collaborations: functional service demands (needs and demands of the service clientele, financial and other resources, variation from type of services currently provided); environmental contingencies (shifting funding, complex treatment modalities, change in client referral, increasing demand for accountability); organizational control strategies (maintenance of internal cohesion, restrictive professional values and organizational norms, degree of boundary spanning); and, coherence of service coordination goals (clarity of goals and objectives, match of goals and objectives to service sector). Further, successful collaborations proceed through predictable phases: (1) a problem setting phase in which is focused on identifying stakeholders and acknowledging their concerns and issues; (2) a direction setting phase wherein stakeholders begin to build a shared interpretation of the collaboration outcomes by articulating a common statement of the problem, individual and organizational values, and resource needs; and (3) a structuring phase in which the common values and goals of the inter-organizational groups are translated into new sets of organizational roles, policies and procedures. In addition, collaboration building also requires designing interactive processes among stakeholders to promote interdependence both in terms of the structure of relationships (e.g. with regard to tasks and systems of accountability) and with regard to the psychological aspects of individuals' beliefs, values, knowledge and styles. Organizational culture as well as structure will need to change.

Lesson #1: Establish a management group.

To guide the development, implementation, and evaluation of the program, a management group was established that includes representatives of each of the collaborating entities. Several key subcommittees were developed (clinical care, staff development, and evaluation). Regular and periodic meetings of the full management group and the three subcommittees are held to assure mutual problem solving, decision-making, and coordination across all facets of the program. It is important to involve individuals at the highest organizational levels possible since without their commitment and articulation of the importance of integration of what had previously been discrete services, necessary resources (allocation of budget, space, tolerance of time necessary for implementation etc.) will not be forthcoming. Neither structure nor culture will change.

Invest the time and effort necessary to develop a mutually defined philosophy of care as well as a strategic plan for implementation

An initial activity in the first year of Whole Life was to fully articulate a program philosophy that reflected an equal emphasis on medical care, mental health and substance abuse treatment, and psychosocial services. This program philosophy was then operationalized into a standard of care protocol as reflected in OB/GYN's quality improvement standards. To orient all of the collaborators to the systems of care in the OB/GYN and Pediatric settings, collaborators heard formal presentations by OB/GYN and Pediatric program managers/supervisors, and observed patient clinics and patient case staffing meetings. The group reviewed the strategic management plan and timelines proposed in the Whole Life grant application, and revised them according to the insights gained during the orientation. The revised standard of patient care (i.e. equal emphasis on medical, mental health and psychosocial services) will direct program implementation as well as the incorporation of evaluation processes to address the new quality improvement program. There should be the same level of formalization, specification, and oversight as standards for patient medical care.

Lesson #2: Strategically facilitate buy-in.

To achieve acceptance of initiating mental health services in the OB/GYN and Pediatric HIV clinics by current primary care providers and psychosocial and case management personnel, a series of planned strategies were employed. At an initial orientation meeting for providers and staff, senior leadership of the collaboration (i.e., Chairman of the Department of Psychiatry, Vice Chair of the Department of OB/GYN, Director of Pediatric Immunology) demonstrated a unified commitment to the importance of mental health services integration. Three staff focus groups were conducted (including one for physicians) to assess such issues as the provider's understanding of the role of mental health within primary care, their perceived impact of the change in workload, and their self assessment of mental health knowledge and skills. Finally, provider knowledge and skills regarding mental health were also assessed using quantitative measures and a ranking form of needs for training.

staff buy-in + needs assessment + training & development

increased system capacity

Lesson #3: Conduct training and staff development activities.

A central strategy for systems change in the Whole Life approach to services integration is to increase the capacity of existing health, psychosocial, and care management personnel within the OB/GYN and Pediatric clinics to detect, assess, and manage the mental health and substance abuse treatment of HIV-infected/affected women and children. In consideration of cost effectiveness, as well as the limited availability of psychiatrists and psychologists specializing in HIV, these existing social workers, psychology fellows, and case managers worked with a dedicated psychiatric advanced registered nurse practitioner to provide the majority of mental health treatment and interventions. A faculty psychiatrist serves as the attending psychiatrist.

To effect this change, several activities have been implemented. The first has been to formally change the job descriptions of the OB/GYN and Pediatric personnel to include the duties of screening, assessing, and serving HIV infected patients with mental health and/or substance abuse intervention needs. Specific responsibilities vary from provider type/discipline, based on occupational role and mental health training (for example, social workers with clinical training conduct screening for psychological symptoms and assessment for provisional psychiatric diagnoses, and provide crisis intervention and individual, group, and family psychotherapies; case managers include mental health and substance abuse treatment in patient needs assessments, and facilitate related service referrals; health care providers include discussion of emotional distress and the importance of adherence to mental health care during patient care visits). A multi-modal staff training/development component has also been implemented which includes formal didactic educational sessions, an intensive family therapy practicum, staff group support and supervision, and individual provider mentoring.

Lesson # 4: Implement screening and case conferencing.

Whole Life has implemented systematic screening procedures to identify mental health and/or substance abuse problems as part of routine patient flow. Beginning with the initial visit to the primary care clinics, and in addition to their medical examinations, patients are screened for indicators of high risk mental health problems by the case managers and social workers. Targeted mental health problems include depression, suicidality, psychosis, substance abuse, physical or sexual abuse, parenting stress, and family dysfunction. When scores on the measures approach established severity thresholds, patients receive in-depth assessments and collaborate in a mental health/substance abuse services plan. Plans are reviewed in a weekly multi-disciplinary case conference attended by health, mental health, psychosocial, and case management staff of Whole Life's collaborators. The use of case conferencing with a focus on discussing mental health and psychosocial as well as HIV health issues has served instructional as well as supervisory and coordinative functions as even the most resistant providers from different disciplines begin to see the interrelated effects of mental and physical health problems on patient functioning and quality of life.

> ...a focus on mental health and psychosocial as well as HIV health issues (has been effective)l...as even the most resistant providers... begin to see the interrealted effects....

Integrate patient record and computerized clinical data management systems

An important strength of Whole Life as a unique site for integrated services research, is its clinical data management system. Essential clinical patient information, typically recorded as clinical notes, is now organized onto scan-able data collection forms; once scanned into the program's computerized data management system, forms then become part of the structured patient medical record. Patient information collected by providers and maintained in this dual computerized and paper-based system include patient baseline medical/health information, case management needs assessment and service plan, psychosocial and mental health assessment and treatment planning, health and psychosocial services provided/utilized. In this way, the patients care team can then simultaneously gather information that can be used for ongoing clinical assessment and at the same time gather data for program evaluation purposes.

Provide on-site and/or linked specialty mental health/substance abuse services to augment ongoing generalist care provided by regular staff

In response to greater than anticipated need for specialty services to address more seriously mentally ill or chemically dependent clients, Whole Life has developed structured linkages to outpatient and inpatient psychiatric and addiction treatment services. Highly distressed patients might be referred for further evaluation to a part-time liaison psychiatrist on-site in the primary care clinics, or to adult and child psychiatry clinics in adjacent buildings. Inpatient psychiatric and/or detoxification treatment is linked within the larger hospital setting and in the community. Routine screening allows more effective targeting of those in need of specialty care and more efficient referrals to care, and less reliance on crisis intervention.

Summary

In the Whole Life program, the properties of several levels of services integration programs have been achieved. Collaborators are equal partners working toward the common goal of fully blended activities that are transparent across the categories of primary care and mental health service categories. Although line authority rests with the respective departments/divisions, grant funding for the mental health integration project is shared. Providers in each department receive cross-training, participate in multidisciplinary case staffs, and frequently share responsibilities for complex, multi-problem family cases. Shared information systems have been developed that infuse mental health-related data and information into both structured medical charts and a computerized patient record database. By being sensitive to the needs of women of color who may also be pregnant and are HIV positive, and by using special data collecting instruments, it has been possible to provide assessment for a population that is often hard to reach while also being able to provide data that might be used for multi-site evaluations as they relate to other governmental funded programs.

Whole Life Project Chronology

October - December 1996

- Grant award received.
- Exchange of resources between Whole Life and OB/GYN formalized. Whole Life provides partial salary support for OB/GYN coordinator and data manager. OB/GYN provides three offices.
- Project coordinator hired - an MSW known and respected by host organization (UM OB/GYN and HIV clinics).
- Whole Life psychiatrist/medical director hired - salary partially supported.
- Consultant agreement finalized with Whole Life evaluator.
- Training subcommittee established to develop formal inservice mental health training curriculum and family therapy externship.
- Evaluation plan reviewed.

January - March 1997

- Whole Life principle investigator named as clinical supervisor of Mental Health Services by OB/GYN Chief of Service thus establishing formal accountability for mental health services with OB/GYN to Whole Life.
- Psychologist engaged as liaison between the project and Division of Child and Adolescent Psychiatry and to provide clinical care to children and families. Salary partially supported by Whole Life.
- Weekly mental health clinical case staffing meeting established.
- Training subcommittee working to develop Whole Life provider training curriculum.
- Routine mental health screening protocol drafted using SPNS/ETAC and local measures.
- Designing of clinical/research data management system begins. Writing Whole Life assessment tools onto scanable forms; database programmed.

April - June 1997

- Revised existing job descriptions of OB/GYN psychosocial counselors and case managers to include mental healthrelated functions and tasks.
- Training subcommittee continues working on Whole Life provider training curriculum.
- Referrals to Whole Life psychiatrist and psychologist PRN begin in OB/GYN clinics.
- Provider training needs assessment tool developed; staff focus group format designed.
- Designing of clinical/research data management system continues.

July - September 1997

- Direct weekly supervision of OB/GYN psychosocial counselors and case managers begins to facilitate mental health orientation to case formulations.
- Training subcommittee continues working on Whole Life provider training curriculum.
- Provider training needs assessment administered, results formulated and feedback provided.
- Designing of clinical/research data management system continues.

October - December 1997

- Direct weekly supervision of OB/GYN psychosocial counselors and case managers continues to facilitate mental health orientation to case formulations.
- Whole Life's continuing application is prepared and submitted.
- OB/GYN psychosocial and case management providers receive first in-service training on Whole Life clinic flow, policies and procedures.
- OB/GYN psychosocial and case management providers receive in-service training on SPNS/ETAC and local protocol.
- Policies/procedures developed for Whole Life implementation into client flow.
- Finalization of mental health protocol.
- Finalization of clinical/research data management system.
- Implementation of scan-able forms that double as patient chart files and research data collection/data entry tools.

January - March 1998

- Formal linkages developed with CMHS-funded and HRSA-funded HIV training programs in Miami (BLCA and AETC) to conduct mental health provider training seminars.
- Formal linkage developed with SAMHSA and NIMH funded University of Miami Center for Family Studies to conduct 20 week family therapy externship training.
- Whole Life's attending psychiatrist/medical director leaves position and is replaced.
- Monthly didactic training programs begin on mental health topics in collaboration with BLCA and AETC.
- Implementation of Whole Life protocol including all SPNS/ETAC and local assessments. All new patients routinely assessed with measures.
- Whole Life attending psychiatrist begins regular, weekly on-site coverage in OB/GYN clinics.
- OB/GYN providers refer patients with mental health problems identified in routine screening.
- Collaborative case planning begins.
- Monitoring of protocol implementation and data entry begins.
- Linkage evaluation component begins.

April - June 1998

- Psychiatric nurse practitioner hired.
- Whole Life data manager leaves and is replaced.
- Monthly didactic training programs on mental health topics in collaboration with BLCA and AETC continue.
- First 20-week family therapy externship begins for psychosocial and mental health providers through UM Center for Family Studies.
- Linkage evaluation component continues.
- Formative evaluation sessions begin with principle investigator/project director.

July - September 1998

- Whole Life continuing application is prepared and submitted.
- Monthly didactic training programs on mental health topics in continue.

- First 20-week family therapy externship begins for psychosocial and mental health providers through UM Center for Family Studies continues.

October - December 1998

- Exchange of resources between Whole Life and OB/GYN continues.
- Formal linkages/exchanges between BLCA and AETC continues.
- OB/GYN psychological and case management providers receive third in-service training on SPNS/ETAC/ocal protocol and Whole Life clinic flow, policies and procedures.
- Second 20-week family therapy externship begins for psychosocial and mental health providers through UM Center for Family Studies.

January - March 1999

- Monthly didactic training programs on mental health topics in collaboration with BLCA and AETC resume.
- Third 20-week family therapy externship for psychosocial and mental health providers through UM Center for Family Studies begins.

April - June 1999

- Monthly didactic training programs on mental health topics in collaboration with BLCA and AETC continue.
- Third 20-week family therapy externship for psychosocial and mental health providers through UM Center for Family Studies begins.

July - September 1999

- Whole Life continuing application prepared and submitted.
- Third 20-week family therapy externship for psychosocial and mental health providers through UM Center for Family Studies continues.

October - December 1999

- Planning begins to create a dedicate women's HIV mental health clinic within the Department of Psychiatry to handle large caseload of mental health patients from OB/GYN.
- Fourth 20-week family therapy externship for psychosocial and mental health providers through UM Center for Family Studies begins.
- Planning begins to evaluate services/outcomes in the new women's HIV mental health clinic.

January - March 2000

- Establishment of a dedicated women's HIV mental health clinic within the Department of Psychiatry is authorized by Chairman of Psychiatry.
- Planning begins for mental health services funding resources after SPNS demonstration ends. Medicaid, Ryan White I, State of Florida and third party billing sources are investigated.
- Fourth 20-week family therapy externship for psychosocial and mental health providers through UM Center for Family Studies continues.
- New women's HIV mental health clinic opens.
- Planning to evaluate services/outcomes in the new women's HIV mental health clinic continues.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by Whole Life, you are welcome to contact the project director and request technical assistance:

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East Boston Neighborhood Health Center

Using Collaborative Case Management to Create Integrated Services

Authors: Michael Mancusi, Mari-Lynn Drainoni and Randy Sell

Introduction

In October 1996, East Boston Neighborhood Health Center (EBNHC) received a five year grant from HRSA to develop and implement the Collaborative Care Management Program (CCMP), a specialized care management/clinical services/primary care integration program for individuals who are living with HIV or AIDS, as well as with co-existing mental health and/or substance abuse disorders.

The goals of the program include: engaging hard to serve individuals in treatment through the introduction of a care manager; increasing integration of primary care, mental health and substance abuse treatment; increasing cost effectiveness and improving outcomes through changing patterns of care; developing critical linkages with community mental health and substance abuse agencies; establishing program replicability and program sustainability.

Location

The Collaborative Care Management Program (CCMP) is an HRSA-funded SPNS project located at the East Boston Neighborhood Health Center (EBNHC) in Boston, Massachusetts. Boston is the state capital and largest city, has a population of approximately 600,000, about 10 percent of the total state population.

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The East Boston Neighborhood Health Center was established in 1975 as a community-owned and operated health center. It serves the low income and working class communities of Chelsea, Revere, East Boston and Winthrop, communities that are geographically isolated from the city of Boston proper by congested tunnels and bridges.

The EBNHC service area includes immigrant communities; populated initially by Italians, and since the 1980's by Central Americans, Brazilians and Asians. Many residents are undocumented, and thus uninsured, while others have private health insurance, Medicaid or Medicare.

The health center provides a full complement of primary care services including adult medicine, pediatrics, obstetrics and gynecology; a full spectrum of specialty care; mental health services; a 24-hour urgent care facility; laboratory, radiology, and other services. EBNHC is affiliated with two hospitals: Massachusetts General Hospital and Boston Medical Center and provides over 300,000 visits annually. It is the largest community health center in New England.

EBNHC has been in the forefront of developing community-based services for both the general population and the special needs populations in its service area. In 1992, the health center decided to extend this experience to develop and implement comprehensive programs for other complex patient populations, including people with HIV and AIDS.

Context of Service Delivery

Ethnicity

The four communities served by the East Boston Neighborhood Health Center range in racial and ethnic diversity. While Winthrop and Revere are moe than 90 percent white, Chelsea's population is only 60 percent white, with 31 percent of Hispanic origin, 4 percent black, and 5 percent Asian. East Boston's population is more than 70 percent white, 18 percent of Hispanic origin, 4 percent black and 6 percent Asian.

Poverty

The health center's catchment area is poor compared to the rest of the state, and three of the four communities are substantially poorer as measured by receipt of public assistance and percent of individuals living in poverty.With the exception of Winthrop, each of these communities has a per capita income below the state average. Thus, a substantial proportion of individuals in the neighborhoods served by EBNHC are living below the poverty level. While the state poverty rate is approximately 9 percent, three of the four communities served by the health center have higher levels of poverty. Revere's poverty rate is 12 percent, Chelsea's poverty rate is more than 24 percent, and East Boston's poverty rate is extremely high at almost 31 percent. Winthrop's poverty rate is less than 6 percent, reflecting its relative wealth in relation to the other three areas.

Poverty rates in the communities served by East Boston Neighborhood Health Center

State Poverty Rate	9%
Rever	12%
Chelsea	24%
East Boston	31%
Winthrop	6%

As a result of the high poverty rates, a substantial portion of the overall population receives some form of public assistance, from a high of 25 percent in Chelsea to a low of 3.5 percent in Winthrop. More than 15 percent of East Boston residents and 12 percent of Revere residents receive public assistance.

Unemployment is a major concern within most of the communities served by EBNHC. While the state unemployment rate is just more than 4 percent, East Boston has an unemployment rate of almost 11 percent, and Chelsea has an unemployment rate of almost 7 percent. Revere's unemployment rate is just over 5 percent. Each of these numbers also represents a substantial decrease in employment since the early 1990s. Winthrop has a lower unemployment rate than the state average, at just over 3 percent.

Substance abuse is significant.... among 25 to 44 year olds, drug related mortality was the cause of 30 percent of all deaths.

Substance Abuse

Substance abuse is a significant issue in the region served by EBNHC. Among 25 to 44 year olds, drug related mortality was the cause of 30 percent of all deaths in East Boston, compared to the state rate of 17 percent for this age group. In terms of admission to substance abuse treatment, substance abuse rehabilitation or detoxification was the fourth leading cause of inpatient admission for East Boston residents.

Of the other three communities served by EBNHC, two had higher rates of admission to substance abuse treatment than the state rate, while one was about equivalent: Substance abuse is a particularly serious problem in Revere, with admission rates to treatment more than double that of the state as a whole. Of the four communities served by EBNHC, Revere has the highest rate of admission to treatment at 3.9 percent. Additionally, injection drug use accounts for the majority of substance abuse in this community. Deaths induced by substance abuse are double the state average in Revere.

In Chelsea, injection drug user admissions to substance abuse treatment programs were 327 percent higher than the rate within Massachusetts as a whole. The rate of substance abuse related deaths in Chelsea is 26 percent of all deaths, compared to the state rate of 15 percent.

HIV/AIDS

The most recent HIV/AIDS surveillance data from the CDC report indicates a total of 13,809 AIDS cases or 924 cases per 100,000 population in 1998, up from 850 cases per thousand population in 1997 in Massachusetts. In East Boston, AIDS is among the ten leading causes of death, but does not equal the rate for the city of Boston or the state as a whole. On the other hand, in Chelsea, the rate of newly diagnosed AIDS cases annually is 22 percent, nearly doubling the state rate of 13 percent. In addition, 138 persons per 100,000 were living with AIDS in Chelsea, while the state rate is 82 persons per 100,000. In Revere, the rate of newly diagnosed AIDS cases annually is almost 17 percent, slightly higher than the state rate. HIV and AIDS do not have the same impact in Winthrop as in the other communities served by EBNHC. The rate of newly diagnosed AIDS cases in Winthrop, is available but the number of persons living with AIDS is slightly lower than the state average, although AIDS-related deaths were significantly higher than the state average.

Context for the Collaborative Care Management Program

CCMP operates in the context of the demographics of the area served by EBNHC as well as in the context of a city that is home of numerous major teaching hospitals and centers of HIV and AIDS care. It also operates in the context of a previous SPNS project at EBNHC. In 1994, the East Boston Neighborhood Health Center received a grant from the Health Resources Services Administration (HRSA) under the Special Projects of National Significance (SPNS) program to develop an integrated model of care for individuals with HIV/AIDS. Project SHINE (Support, Healthcare, Intervention and Education) was designed as a community-based program that uses a multi-disciplinary team approach to caring for people with HIV/AIDS. CCMP was developed to complement Project SHINE, with a goal of extensive integration and coordination between the two programs. Project SHINE was also expected to serve as CCMP's primary referral source of HIV-positive individuals who also have severe mental health and/or substance abuse problems.

Lessons Learned

Lesson #1: Taking a program from theory into reality is difficult.

Developing a program from theory into one with an active case load, active referral sources and a common

The use of formal agreements for linkage has been seriously questioned....

understanding among program and referring staff as to the basic tenants purposes and referral procedures is extremely difficult. One by one, each obstacle to implementation was confronted and favorably or reasonably resolved before proceeding. These barriers included the scarcity of building space, model revisions within collaborating agency, and contract negotiations snags with linking organizations.

The investigators learned that the time required to complete the linkage development process from initial contact to an executed letter of agreement (LOA) has often been lengthy. It became apparent that existing linkages are ineffective when the linkage cannot be actualized with referrals of several patients around which to pilot and test the strength and viability of the linkage. They now know that an executed LOA in the absence of a solid connection with service delivery staff of an agency will mean very little at admission and discharge of referred patients.

The project has recognized that referral numbers have lagged well behind expectations. The original target patient load was 100, but as of early 2000, had reached only 40. It is believed that patient numbers are small as the result of collaborating agency's patient load remaining consistent, which in turn can be traced to the growing number of new, hospital-based HIV service programs. That is, patient load has not increased because of the slower-than-expected growth of HIV primary care at the health center. Most importantly, low patient load will have a significant impact on the project's ability to secure third party reimbursements and managed-care contracts, and develop viable linkages. For example, it is difficult to form strong alliances with agencies if the relationship is not used and tested. More patients in the program would have afforded a greater opportunity to interact with and strengthen collaborations with linkage partners.

Lesson #2: It is the staff that implements linkage.

In April 1998 when the first CCMP patient was admitted to a local collaborating hospital, staff realized the linkage agreement with the hospital was not working as originally intended. As a result they decided to involve direct service staff when negotiating affiliations. This represented a shift in focus in the linkage development process and procedures from the administrative/executive level to the service delivery level as the first and most effective level at which to initiate and operationalize linkages. What was important was how the process of linkage development is implemented and who is included. While agency management needs to be involved in the contractual process, there also must be involvement of the direct care staff. They are the ones who actually make referrals and provide services and coordination if linkages are to be effective. Service providers from both agencies should be included early in the process in order to create and maintain an ongoing relationship. The use of formal agreements for linkage has been seriously questioned. Staff were concerned about the effectiveness of contracts that did not filter down to the people who are doing the work.

....Staff were concerned about the effectivenes of contracts that did not filter down to the people who are doing the work.

In September of 1998 program staff again reviewed the linkage process. At that time, they shifted from an exclusive focus on formal linkages (using letters of agreement) to examination of the importance of informal and operational approaches.

Lesson #3: Cultural competence requires continual reassessment.

In June of 1998, a decision was made to pull cultural competence out of the formal evaluation plan. This decision was later reconsidered on the basis of need and commitment in particular to Spanish-speaking populations. A cultural competence coordinator was appointed in recognition of the need to consolidate this vital program component. In October of 1998 a cultural competence evaluation plan was completed. A decision was made to discontinue cultural competence training for the mental health staff in favor of redirecting energy toward determining why so few referrals of Latino patients had been received by the program. Prior to this time, three training sessions had been held for East Boston Neighborhood Health Clinic mental health and social service staff.

Despite cultural competence training, Latino referrals have not increased.

By April of 1999, program staff recognized the need for overlap between addressing cultural competence concerns and linkage development in order to achieve the goal of increasing Latino referrals. This led to a shift from a theoretical approach to a more operational look at providing culturally competent care.

Hiring an additional care manager increased patient assignment options. It became possible to accommodate language, cultural, gender preferences and diagnostic considerations when making care manager assignments for new participants. However, when the trilingual care manager resigned, the program found itself without the ability to immediately serve non-English-speaking clients. But due to the low numbers of such referrals, the program was able to still consistently serve its patient population. The program referred the few Spanish-speaking patients to a fluent HIV case manager from a collaborating agency. The project also renewed a contract with a private outpatient mental health practice in East Boston with Spanish-speaking service capacity. This agency was successful in adding several new bilingual staff members and has welcomed new referrals from the health center. Unfortunately the number of Latino referrals has not increased despite cultural competence training, the existence for sometime of a senior-level, trilingual, bicultural care manager and a HIV patient population that is 27 percent Latino.

Lesson #4: Care managers can provide unique services.

By developing a theoretical framework from individual relationships between provider/client to provider to patient in his/her environment, program staff defined the role of care manager and differentiated this role from the role of case managers and strictly traditional individual psychotherapists. Theoretical concepts such as the holding environment and parallel process, as well as systems theory, further enriched and deepened the process of supervision as well as differentiated the role of care manager and case manager.

The care manager, as the role was originally conceptualized, was a person with a masters degree with demonstrated expertise in triple diagnosis. This model has the potential to prove both clinically effective and cost effective, as the care manager coordinates all care from client's entry into the system, and follows the client wherever he or she is. Care managers work closely with all other individuals involved with the client's care, including physicians, other mental health and substance abuse providers, and support service providers. The care manager may also serve as the primary mental health provider if appropriate.

Significant progress has been made in the development and field testing of the specialized care manager role. It has been especially challenging to construct and implement customized service plans and continuously adjust the care manager role for each participant. Thus considerable time and energy have been expended during clinical supervision, peer advisory meetings, and weekly clinical team meetings examining, from theoretical and pragmatic perspectives, the evolving iterations/reiterations of this care manager role, which is the cornerstone of the project.

In April of 1999, project staff discussed the overlap of services with collaborating agencies. This was necessary in order to create a truly interdisciplinary treatment team and reduce role confusion between HIV case managers and the care managers. It was hoped that communication, cooperation, and camaraderie would improve. Project staff recognized the inherent risk of inadvertently creating parallel program models targeting the very same patient population, and assessed the additional risk of inadvertently creating the very fragmentation they had set out to address and reduce. The result of these concerns was a plan to create a diagnostic evaluation clinic in an effort to engage clients immediately in the treatment process and to speed up the access to critical services. By creating this newly constituted multidisciplinary team, for the first time, the entire range of providers who serve the relevant patient population were working together at the health center.

The care managers provide the primary brokerage for the implementation of a more integrated model of care. They provide weekly clinical supervision to the case managers, informal peer case review to the case managers and HIV nurse, trainings on a relevant clinical issues, and steady service and leadership for the diagnostic evaluation unit, a progressive model of immediate engagement of newly diagnosed HIV infected individuals. Care managers also, take the lead in facilitating internal care coordination meetings, attend treatment and discharge conferences, and work with patients to negotiate the legal system or access needed services. Referring agency staff now confer with a care manager whenever making a new referral, thereby removing the guess work relative to program criteria and ensuring the development of an engagement plan. All of these coordinated efforts promote the project's goal of reducing fragmentation and improving access while simultaneously decreasing role confusion and duplication of effort.

East Boston Neighborhood Health Center Project Chronology

October 1996

- Grant award received. Begin a search for a qualified evaluator with whom to execute a consultant contract.
- Team developed for program implementation.

November 1996

- Negotiate with local mental health association to co-sponsor and co-manage the Collaborative Care Management Program.

December 1996

- First care manager hired. Program development continues.

February 1997

- Implementation team members plan to initiate meetings with other agencies to discuss affiliations and linkages in conjunction with the grant objectives.

January 1997

- Negotiation with Medicaid Working Group (MWG) of Boston University to serve as project evaluator begins.

February 1997

- Negotiate contract with a small managed care organization serving individuals with disabilities, HIV and AIDS, to manage the care of a segment of EBNHC primary care patients.

March 1997

- Tools and procedures for initial program implementation are finalized, including referral forms and referral process.
- Achieve same day access for all EBNHC patients to local treatment center.

April 1997

- HRSA/SPNS site visit.

May 1997

- First of a series of three training sessions in cultural competence presented to the staff of the Mental Health/Social Services Department.

June 1997

- Preliminary data collection tools researched and recommendations made: 1) screening, outcome, quality of life and satisfaction measures; 2) develope service linkages in the community for mental health and substance abuse treatment.

July 1997

- Complete Department of Mental Health (DMH) IRB process in conjunction with goal of admitting DMH eligible patients, thereby beginning to address the need to contract with payer sources to sustain the program beyond the grant funded period.

September 1997

- IRB approval by DMH Central Office Research Review Committee received.

October 1997

- Second care manager hired. Care managers become increasingly involved in program development and the operationalizing of the data collection process.
- Care managers begin to attend CCMP planning meetings.
- CCMP goes live and officially starts accepting referrals.
- Begin weekly evaluation meetings, which provided a chance to discuss progress of data collection. Discuss amount of data to be collected and resulting client burden. Decision made to eliminate several local evaluation tools from data set in an effort to decrease client burden.

November 1997

- CCMP begins reviewing referrals in accordance with preliminary admission requirements.
- First linkage survey administered. Staff at EBNHC interviewed and concerns about referral process and access to CCMP emerged.

December 1997

- Develop criteria and process for discharge and inactive status.
- Care managers finalize intake forms. CCMP data binder is created.
- Finalize project data codebook, data collection and data submission procedures.
- First client enrolled in the program.

March 1998

- Linkage process moving slowly. Start weekly linkage meeting to review the progress of affiliations and assign tasks for the week. Results in drafting of guidelines for the linkage development process.

April 1998

- First CCMP patient admitted to collaborating hospital. Realize that linkage agreement not working as originally intended. As a result decide to involve direct service staff when negotiating affiliations. This represents a shift in focus in the linkage development process and procedures from the administrative/ executive level to the service delivery level as the first and most effective level at which to initiate and operationalize linkages.

May 1998

- First data submission, including linkage data, submitted to ETAC. Data is clean.
- Substance abuse consultant hired to provide expertise in addictions to team. This consultant is an important addition as a balance to the more psychodynamic approaches of the care managers.

June 1998

- Decision made to pull cultural competence out of formal evaluation plan. This decision was later reconsidered on the basis of need and commitment to population.
- Implement participant incentives to facilitate the completion of data collection. Although some staff have initial reservations about this policy, it increases the amount of data collected. These reservations are about the complications associated with mixing financial incentives with clinical work, especially with a multiply challenged patient population. The policy also helped clarify the historical tension between clinical work and data collection. Staff decides upon using food vouchers over cash incentives.
- Re-examination of team roles reveals the need for an administrative assistant
- Move to new building.

July 1998

- Site visit by ETAC. As a result, a procedure for performing process evaluation added to evaluation and dissemination plans.

July 1998

- Develop HIV risk criteria, which results in our requesting and gaining HRSA approval to admit the “not yet positive” category of patients to the CCMP. This will potentially strengthen our evaluation with higher referral numbers and a greater likelihood of developing a comparison group.
- Refer first patient to collaborating treatment facility after negotiating same day access. Linkage with agency is actualized.

August 1998

- Develope local evaluation activities. Local evaluation activities will take place in five domains: overall process evaluation, cost effectiveness, cultural competence, role of the care manager, replicability in the current health care environment.

July/August 1998

- Collaborating mental health association declares intention to terminate contract to jointly fund and manage the CCMP as a result of significant changes in DMH funding.

September 1998

- Clinical supervision re-examined.
- Neighborhood Health Plan (NHP) Intensive Case Management contract awarded.
- Review program linkages again.
- Creation of a monthly integration meeting to better coordinate clinical and evaluation components of program.

October 1998

- Administrative assistant hired.
- Draft of cultural competence evaluation plan complete. Discontinue cultural competence training for the mental health staff.
- Second round of linkage survey given to EBNHC staff.
- Second data submission submitted to ETAC. Data clean.
- Administrative assistant resigns. Administrative tasks become increasingly burdensome for the care managers and project directors.

January 1999

- Implementation of policy and procedures in the assessment and management of risk factors in patient care and development of corresponding risk management/special clinical review form.

- Draft cost effectiveness evaluation plan and complete first cost-effectiveness data run.

- Collaborating agency again implements revisions to the program model. This changes the way in which CCMP interacts with agency.

- East Boston Neighborhood Health Center files for Chapter 11 Bankruptcy protection potentially imperiling the program. Neither the CCMP staff in particular nor the mental health/social services staff are directly affected by the planned reduction in force and subsequent health center reorganization.

February 1999

- Collaborating agencies develop a system for coordinating the collection of data common to both projects. Represents an improvement in the collaboration on data collection between the two projects, thereby reducing patient burden in the process.

March 1999

- Reinitiate collaborative meetings with the Community Medical Alliance Program of NHP to redefine roles, clarify misperceptions and discuss patient care.

- Graduate intern agrees to assist with data entry in preparation for third data submission to ETAC while program seeks to hire an administrative assistant.

April 1999

- Decide to redesign the linkage survey. Previous survey did not reflect the impact on staff perceptions of new affiliations with mental health and substance abuse agencies and does not survey outside agencies' satisfaction with linkage development process.

- Cultural competence and cost effectiveness concept paper drafts are distributed to the integration team.

- Discuss need for overlap between cultural competence, linkage development and the goal of increasing Latino referrals.

April 1999

- Discuss need for overlap meeting between collaborating agencies. This process precipitates a needed mid-life review of the program, including lessons learned in several key areas for the project.

May 1999

- Third care manager hired.

- Full day meeting in Boston with ETAC to discuss evaluation process and procedures.

- Care managers begin to formally outline and develop the conceptual model of the role of the care manager.

- Third round of data and second round of linkage data submitted to ETAC. Data clean.

June 1999

- Team decides to look at referral process and base in attempt to increase program numbers. This results in a broad re-examination of systems issues at the Health Center including those between the SPNS I and II projects and a redefining of our audiences and potential sources of increased referrals.

- After carefully considering issues such as patient burden, reliability and duplication of effort, decision made to apply to HRSA for an exemption of the requirement to administer the PPQ to our project participants. Decision made to rescind the request once the implications for modification to the database, data collection tools and data submission process were fully assessed and understood. HRSA project officer offers the possibility of additional funds to assist with this data collection effort. Consider increasing the incentives budget to ease patient burden, and continue to explore and address our concerns about instrument validity and the use of clinical judgment as to the timing of the PPQ administration to avert, whenever possible, adverse reactions.

July 1999

- First meeting collaborating agency staff held to identify areas of progress, as well as significant barriers to progress at the midpoint in the project. Barriers to effective communication, role confusion and access to services are cited as the most critical issues. Case examples illustrating the efficacy as well as limitations of the model were provided.
- Key outcomes of the meeting are the deciding factors to construct a new multidisciplinary team created by combining collaborating agency staff and to plan and implement a diagnostic evaluation clinic to be staffed by the HIV nurse, the CCMP care managers and the HIV case manager. These two measures are intended to improve patient care by decreasing fragmentation, increasing communication and distributing patient care-related tasks among team members, thereby reducing duplication and role confusion. This is viewed as a major accomplishment.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by East Boston Neighborhood Health Center, you are welcome to contact the project director and request technical assistance:

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HIV Cybermall, Northeast Valley Health Corporation

A Wide-area Computer Network for Comprehensive HIV Service Delivery

Authors: Mark Henrickson, Judy Mayo and Peter Messeri

The information in this article is based on interim findings from the first three-and-a-half years of a five-year demonstration project. Final results of the evaluation will be available upon completion of the grant cycle in Fall 2001.

Introduction

The difficult task of managing the medical care of HIV-positive individuals is frequently complicated by problems stemming from substance use, mental illness, poverty, and cultural and linguistic differences. The array of services needed to cope with the disease and related complications are invariably distributed across multiple agencies. Minimal coordination across agencies may impede accessing services and compromise the efficiency and effectiveness of services delivered.

The HIV Cybermall Project seeks to improve the coordination of services delivered by multiple agencies through a creation of a wide area computer network that links the major HIV care providers in the project's service delivery area. Personal computers at each participating site are connected to a central server that permits the sharing of client information and instantaneous referral and scheduling of appointments between agencies. E-mail and other network software functions promote improved communications between staff in different agencies. Transportation is a crucial component of HIV Cybermall. It complements the appointment scheduling and client tracking to create an online referral network.

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The experiences of the HIV Cybermall Project provide valuable lessons related to the selection and installation of networking hardware, training and use of network services by staff of participating agencies and the vital role of agency representatives and consumers in designing a network that is trusted and used by agency staff and clientele.

Collaborating HIV Cybermall agencies

Primary Care Clinics	Northeast Valley Health Corporation (Lead Agency) El Proyecto del Barrio AIDS Healthcare Foundation Valley Community Clinic Olive View Medical Center High Desert Hospital
Substance Abuse Treatment Programs	Tarzana Treatment Center Cri-Help Western Pacific Rehabilitation
Psychosocial Service Agencies	Bienestar Latino AIDS Project Hands United Together Being Alive Homeless Services
Dental Clinic	Avalos Dental Services (a Division of NEVHC)
Home Health Care Hospice and Residences	Trinity Care Home Pharmacy of California Homestead Hospice and Shelter

Service area and collaborating agencies

The HIV Cybermall Project links 17 agencies that care for HIV-positive people living in the San Fernando and Antelope Valleys north of Los Angeles. This service delivery network serves a potential 6,000 HIV-positive residents spread out over a region of 4,200 square miles. Many clients of the 17-agency collaboration are diagnosed with either or both substance abuse and mental health disorders as well as HIV.

The 17-agency network forms a collaboration that offers a full continuum of HIV-related services. Many core services are offered at multiple settings and several organizations have culturally-specific programs for African-American and Latino communities. The network includes agencies engaged in street outreach and offer active users a choice among substance abuse programs with several treatment modalities and treatment philosophies. Several organizations within the HIV Cybermall network have expertise working with dually- and triply-diagnosed clients as well as the post-incarcerated population.

Intervention

HIV Cybermall is composed of two major components designed to coordinate care, reduce duplication of services, while increasing access to the full complement of HIV-related services offered by collaborating organizations:

1. A private, secure wide-area computer network (WAN) that provides high-quality, high-speed digital connectivity for an online referral system and online meetings and case-conferencing. The network uses Microsoft Office software on the NT4.0 platform. The network is currently used for internal e-mail, interagency appointment scheduling and transportation scheduling. Internet access and client tracking. Common intake on a standardized client intake form and other

electronic templates permit case managers paperless transfer of client information across the network. Other functions in the planning stage include case conferencing and online meetings using Microsoft's NetMeeting videoconferencing software.

2. A transportation service for clients of HIV Cybermall agencies consisting of a full-time transportation coordinator for the region who is a single point of contact for taxi vouchers, bus passes, and disability services and who serves as dispatcher for a system of HIV-specific van transportation. The transportation system preexisted the implementation of the HIV Cybermall project, and is funded by Title II of the CARE Act. Transportation, which was not funded for this project, is an essential component of the enhanced communications network.

Dissemination of information about the HIV Cybermall Project was accomplishedin part through a public website (www.hivcybermall.org) that serves as an Internet resource directory for clients and provides services for clients on the Internet.

The project also served to lay the groundwork and served as the information technology infrastructure for a separate (county-funded) organizational initiative to improve, standardize and expand case management services across the region by hiring case managers at all sites (15.8 FTEs), increasing training requirements, developing shared policies and procedures and quality management.

The intervention was developed over three years by two boards: an Interagency Advisory Board (IAB) consisting of designated representatives of each of the 17 HIV Cybermall agencies; and a Consumer Advisory Board (CAB) consisting of between eight and ten HIV-positive clients of the 17 HIV Cybermall agencies.

Staffing levels for major HIV Cybermall activities

Planning and Development Phase	**1.20 FTE**	Program management
	.70 FTE	NEVHC support staff
	40	Days for outside consultant
	26	Meetings per year for IAB and CAB
	$1,130	Per site cost for PS and associated software
	$22,600	Installation of HUB and network connections
Operational Phase	**0.2 FTE**	Program management
	.25 FTE	Network administrator
	10	Hours/year for outside consultant
	$30,252	Annual operating costs (includes internet service, service contract and network charges)
Transportation Services	**1.0 FTE**	Transportation coordinator
	1.0 FTE	Van driver

Staffing

Northeast Valley Health Corporation is the lead agency for HIV Cybermall. This agency employs the staff and consultants for planning and implementation of the network. NEHVC is responsible for maintenance of the operational network; and it is the home for the transportation services.

Network Implementation

Planning of the network formally commenced in November 1996 with the first meeting of the Interagency Advisory Board. After a lengthy request-for-proposal (RFP) process, the IAB awarded GCG Computers (now TeraTechnologies) the contract to develop the network during August 1997, ten months into the grant cycle. The network, which operates over dedicated lines, began pilot operation in three of the 17 agencies in December of 1998. It expanded to an additional five agencies in March of 1999 and will expand to include all agencies by the end of 2000. The HIV Cybermall website became operational in June 1998. The first intake form was transmitted on December 1998 and by July 2000, an equivalent of 4.8 million pages of double spaced text had been transferred across the network. See the accompanying timeline for more detailed chronology of HIV Cybermall activity.

Lessons Learned

Lesson # 1: Agency buy-in is a continuing process.

Central to HIV Cybermall's efforts in promoting agency buy-in was the formation of the Interagency Advisory Board at the initiation of the project. The IAB was actively involved in developing policy and procedures for all aspects of network operations. The board selected outside consultants and designed the forms and protocols for the network's client referral and information sharing functions. Nonetheless, convening regularly meetings of the IAB is only one part of maintaining agency involvement.

The single most important aspect to this project is the sharing of authority and responsibility that occurred from the very outset. Although the lead agency was fiscally, legally and practically responsible for the project, the IAB was given both symbolic and practical authority from the very beginning. This authority was made real, for instance, by the creation of a personnel committee to recruit, interview and recommend project staff for hire.

A small number of agencies may sustain active participation without outside encouragement, but the more usual pattern is intermittent engagement. An agency's involvement in network activities will ebb and flow in response to more pressing demands on limited staff time and resources. HIV Cybermall staff learned that reaching out to each agency through periods of change, low participation, or conflict resulted in high returns in maintaining network involvement of all agencies still in business. Periodic presentations to agency heads also proved effective in sustaining interest and cooperation; as did a robust agenda of computer network training programs.

The single most important aspect to the project is the sharing of authority and responsibility...

Lastly, there was a great deal of mistrust of electronic communications from the beginning of the project. Encouraging—in fact requiring—participation from all the agencies on very practical levels not only encouraged buy-in, it also created trust. Selling network security was central to agency buy-in. At the request of the agencies, a presentation by an expert in security was arranged. This was critical in convincing the users that network security would maintain the confidentiality of client records created and transmitted electronically between agencies. An important follow-up was to urge that network staff demonstrate in both word and deed that security is of highest priority.

Lesson #2: It's not easy being small.

It is particularly difficult for nonprofit agencies with little or no technical expertise to work within the fast-paced, big money arena of information technology. So many technology companies are big, it is easy for a project's plans to get out of control. What may be a large expense for the agency is small change to them. Securing a qualified consultant to design and install a suitable wide area network was a daunting task.

An initial request for proposal resulted in four bidders, none of which were found acceptable. The second request was more detailed. Inquiries were mailed and faxed to six local business associations and more than 20 consultants with successful results. The IAB chose a computer consulting company that appealed to them personally, demonstrated technically proficiency and presented the most realistic pricing plan.

From the selection process HIV Cybermall learned:

- Case managers and mental health professionals are trained to make accurate assessments of people. Put that ability to use by having them conduct personal interviews of prospective consultants.

- Case managers are rarely trained in technology and frequently have an innate suspicion of technological solutions to human problems. It is essential to ensure that appropriate nontechnical language is used in the development and presentation of technological solutions to human service workers if end-user buy-in is to be achieved.

- Make sure the selection is a group process and involves the entire collaborative, not just one agency or project. Failure is almost guaranteed if all sites are not included in the selection process.

Lesson #3: Use workhorses, not exotic zebras.

Over the course of planning and implementation, HIV Cybermall learned several hard and fast rules about technology and human nature. The first rule: use standardized, time-tested hardware and software—nothing too new or too unusual. Don't try out the brand new version of a software package. Wait until it has been out long enough to be tested and debugged. Let others with more resources, who can afford to take risks, try it out and make certain it meets the needs of your group. For example, Windows 2000 may be terrific, but it is not adopted as widely as the 98 version and would have been a bad choice for HIV Cybermall. Standardized hardware and software is much cheaper and more bug-free than custom, and training costs and troubleshooting and technical support are more available and cheaper.

Don't put client data on the network for several months. Allow enough time for staff at each site to become familiar with security procedures and to verify for themselves that all workstations are physically secure. End-users always do surprising things, so allow time for those to happen before adding client data to the system. For example, one staffer disconnected his computer and took it home; another spilled coffee on an expensive router; one office replaced the NT platform with the insecure 98 one without telling anyone (it was discovered during a site inventory). Instill two cardinal rules of network security—never write down or share your password, and never leave your workstation unlocked. But no matter how basic the software and hardware, keep things simple and prepare for continued training.

Implementation was much slower than anticipated. Budget considerations didn't allow for a business-style, over-the-weekend event, rather it was a gradual process. Expect agencies to differ greatly in the time they will require to plan and install network hard ware and software. Staff turnover and personal time off of staff took must also be factored into planning hardware installation.

Lesson #4: Staff adapt very gradually to network activities.

Communication functions of the network were adopted much more quickly than its coordination functions. Network staff were quick to adopt e-mail for interagency communications and to explore the Internet for information. The migration of scheduling for transportation services to the network also proceeded smoothly. Agency staff were much slower to use the new shared functions and procedures—the online referral network and sharing of client information.

The original research design of the project called for a two-wave installation, where half the agencies would have access to the system for 18 months, and half would not. This was unsuccessful, because it required case managers both to retain their former referral patterns with some agencies, and add the new system with others. Not surprisingly, the outcome was that the innovation was not used, since it required extra effort as opposed to the familiar, tried-and-true method. Use of the network for referrals only works well when all agencies are on the network. Intuitive software and training to use that software were the essential ingredients that resulted in network utilization. Training must be basic: some staff, for instance, could not type and required basic instruction in keyboarding.

Training Activities

June 1998 to March 2000

15 group training sessions (ranging from .5 to 5 hours)

51 hours of group contact

74 individuals trained

394.5 total person-hours of training

5.3 hours of training per trainee

20 one-hour individual sessions with 15 individuals

Lesson #5: Never underestimate staff churning and agency dynamism.

The amount of staff training required was grossly underestimated, not simply because agency staff were unfamiliar with the software and hardware, but because agency staff turnover was so high. Nonprofit agency case managers are primarily entry level line staff, and generally not well paid. Consequently, when opportunities came to move up or out, they did. Training and retraining at the same agency was an unexpected and time consuming necessity. In addition the not-for-profit HIV service agency environment was a dynamic one at the time, and agencies merged, collocated and closed, sometimes unexpectedly. This required an unexpected amount of installation and reinstallation of equipment, and created billing and service confusions that contributed to the implementation delay.

Lesson #6: Controlling utility costs is the most demanding task.

Monthly operation costs are the key to cost control. Bidding, negotiation and sign-off on agreements for installation and maintenance must be negotiated by a person with necessary professional experience and expertise. The person negotiating network contracts should have a good working relationship with his or her counterpart in the utility company. The network manager's accounting department must also be instructed in how to monitor monthly bills. Utility billing practices are very difficult to decipher. Every expense must be questioned, since these technologies and billing for them are often new to the utility as well.

HIV Cybermall Project Chronology

June 1996

- Agencies are first solicited for participation in the project as part of the grantwriting process. • Agencies are selected based on existing or desirable referral patterns.
- Agencies are promised a computer as incentive for their participation, and to ensure that the agencies had compatible, current hardware capabilities.

August 1996

- As part of the grant review process, the lead agency is required to delete enhanced transportation from the original proposal.

November 1996

- First meeting of the Interagency Advisory Board (IAB). Committees are formed to hire a project manager, to develop a Consumer Advisory Board, to design a uniform intake form, to oversee the development of an evaluation tool and to write a request for proposal (RFP) for software design.

January 1997

- Uniform intake form approved by the Interagency Advisory Board.

February, 1997

- Project manager hired.

March 1997

- First draft of the RFP reviewed by the Interagency Advisory Board.

- The first meeting of the Consumer Advisory Board focuses on transportation and security issues.
- The first issue of *Linkages*, the project newsletter, is published.
- Begin meeting with Information Systems personnel at individual agencies to learn about their existing computer systems (where they exist).

April 1997

- First draft of the software RFP is presented to the Interagency Advisory Board and Consumer
- Advisory Board for review. The RFP is mailed directly to 30 potential vendors, six local business associations, and advertised on USENET, in the *Los Angeles Times*, the *Daily News* and the *San Jose Mercury News*.

June 1997

- Four companies respond to the RFP and their proposals are reviewed by a subcommittee of the Consumer Advisory Board and Interagency Advisory Board.

July 1997

- The IAB is not satisfied with the four companies bidding and votes to reissue the request to new vendors for bidding and to arrange for personal interviews with all bidders.
- Olive View staff is contacted to encourage their participation in the project. They have not attended any meetings since signing the letter of collaboration and are a central referral destination.
- RFP reissued for the design of the network.

August 1997

- GCG Computers is selected as the computer consultant for the project from a pool of six bidders which included some of the largest companies in the industry as well as smaller, local consulting concerns.

September 1997

- While contract negotiations between GCG and NEVHC proceed, GCG sends two experts who visit four sites and complete a workflow analysis preparatory to developing the optimal software solution.
- GCG provides telephone consultation regarding network security. Software needs are evaluated and it is determined that the latest version of Microsoft's Outlook will provide the functionality needed.

February 1998

- Transportation coordinator hired.
- First computer for the HIV Cybermall is purchased and installed at Hands United Together. Computer removed from premises by agency director (he took it home). Project director drafts legal agreements between agencies and NEVHC regarding network security and maintenance of equipment.
- GCG obtains bid from GTE for the frame-relay design that the IAB had selected. It is too high; two additional bidders are contacted. Pacific Bell has the best infrastructure and bids half of GTE's price. Negotiation begins for the frame-relay network.

March 1998

- Begin contacting local HIV client information providers in minority HIV agencies and in the large community-based AIDS organizations to start the development of the website.

April 1998

- Purchase and install computers in beta agencies (NEVHC HIV Division, Homeless Division and Dental Services)
- GCG makes site visit to meet with the IAB and describes the frame-relay design and network operation. A website addition to the project is proposed and endorsed, in concept, by the IAB.

May 1998

- NEVHC hires .25 percent FTE as network specialist to install the frame-relay network.

June 1998

- Two servers purchased and installed.
- Website is up and available while under construction.
- Computers purchased and installed at Bienestar, Valley Community Clinic, and Tarzana (all three at the Valley HIV Center location) and Home Pharmacy.

July 1998

- Begin training frontline staff in use of HIV Cybermall. Provide classroom introduction to personal computer care, the Microsoft Office Suite and security procedures.
- Meet with Pacific Bell team, including technical, sales and billing people to speed up negotiating the agreement and to arrange for proper billing procedures. GCG is authorized to represents NEVHC's interests in the negotiations.

August 1998

- Hold three training sessions at UCLA's biomedical library's microcomputer lab. One is conducted by GCG staff. Two are remedial sessions for those least familiar with computers. They are led by staff and a former Consumer Advisory Board member.
- Contract between GCG (now TeraTechnologies) and NEVHC is signed.

September 1998

- TeraTechnologies proposes forming a true public-private partnership to develop income for the HIV Cybermall over the long term once funding has ended. A mission statement is written. (The complexities of website based interstate fundraising for a not-for-profit entity will prove fatal to this proposal, and for the website itself.)

October 1998

- TeraTechnologies distributes 8,000 promotional stickers at the Washington DC AIDSWALK; NEVHC hands out 1,000 at the Los Angeles AIDSWALK.

November 1998

- The last of three agreements is signed with Pacific Bell. Internet services for case managers has been added to the network for $230 per month.

December 1998

- Routers installed at three beta sites by Pacific Bell.
- Two of three trained beta site HIV Cybermall staff announce they are leaving their agencies.
- The first intake form is filled out and transmitted on the network between the HIV Division, Avalos Dental Services and NEVHC Homeless Health Services.
- One week after the network is up and operating, unauthorized entrants into the server site who were installing a separate system for an unrelated program disconnect critical cables, disabling the system. A variance is filed and processed. It takes 13 hours for network specialist to get the network back to operational condition.

January 1999

- HIV Cybermall van driver hired.

- TeraTechnologies returns to reconnect the network and to assist in setting up the backup and recovery systems using ArcServe. The system becomes operational again.
- Computers installed at Tarzana's Reseda site and at Western Pacific Rehabilitation's Methadone clinics.

February 1999

- Computers at Tarzana and Home Pharmacy connected to the WAN.
- New transportation coordinator hired.
- Consultant hired to prepare an application for a transportation grant from the state.

March 1999

- On the day Pacific Bell arrives on site to connect the routers for the Valley HIV/AIDS Center, the Center informs HIV Cybermall staff that it is closing and staff is relocating. All three computers picked up by new van driver and returned to NEVHC premises.
- Computer installed and connected to WAN at Trinity Care. Computer from Valley HIV Center closing is installed at Valley Community Clinic.
- Application for state funding for purchase of two vans submitted.
- A three to four minute segment on the website airs on CNBC.

April 1999

- TeraTechnologies makes final visit for the installation for the first-wave agencies. HIV Cybermall webmaster instructs staff on how to program the software.
- Recommendations from agencies who have been using the network since January are used to modify and fine-tune the network.
- NEVHC case manager is connected to the WAN.

May 1999

- Computer from Valley Center closing is installed at Bienestar's new location and connected to the WAN, completes first wave installation.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the HIV Cybermall project, you are welcome to contact the project director and request technical assistance:

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Chicago HIV Risk Reduction Partnership for Youth (CHRRPY), Cook County Hospital

Identifying HIV-positive Youth and Transitioning Them into the Health Care System

Authors: Jaime Martinez, Doug Bell, and Randall Sell

Introduction

When CHRRPY was initially funded, the Chicago Department of Public Health (CDPH) estimated that 3.4 percent of 21,000 projected cases of HIV infection would be seen in youth 10 to 19 years old. However, HIV counseling and testing efforts within Chicago had identified fewer than 15 HIV-positive youth annually. In the CDPH testing sites, of 3,679 youth age 12-19 presenting for testing, only four were HIV positive. It is unclear how many returned for post-test counseling and results, although statistics from CDPH showed that fewer than 50 percent of individuals who got tested for HIV actually returned to get their results. It was also unclear whether these youth have accessed other health services. The mission of CHRRPY was to identify and care for the 700 Chicago youth who are falling through the structural and legal gaps in the health care system.

A needs assessment of the system before the project was initiated indicated three major barriers to service: (1) many testing sites are not in youth-friendly environments and personnel are often perceived as insensitive by youth, (2) there is no support system that would allow youth to overcome their fear and anxiety when testing for HIV, (3) communication between counselors and youth being tested is weak. Providers are perceived as judgmental by youth and providers' knowledge and understanding of youth is limited.

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Model of Care and Services

CHRRPY was created to address the major barriers youth face when accessing services. CHRRPY used an outreach team that included an outreach worker/phlebotomist (called a case finder), who was trained to be sensitive to adolescent issues, and a youth peer educator. They traveled to various agencies that served high-risk youth throughout the city of Chicago and provided on-site HIV education, counseling and testing, and referral services. These outreach teams were developed to link HIV-positive adolescents to primary care services. To conduct its outreach services, the CHRRPY project linked with community agencies including: a social support agency serving gay youth, an HIV prevention agency, an alternative educational program for students who had dropped out of school, an alternative high school, several agencies providing services to homeless youth, an agency with programs for gang members and substance abusing youth, an agency that houses youth detainees, and the state agency responsible for guardianship of wards of the state.

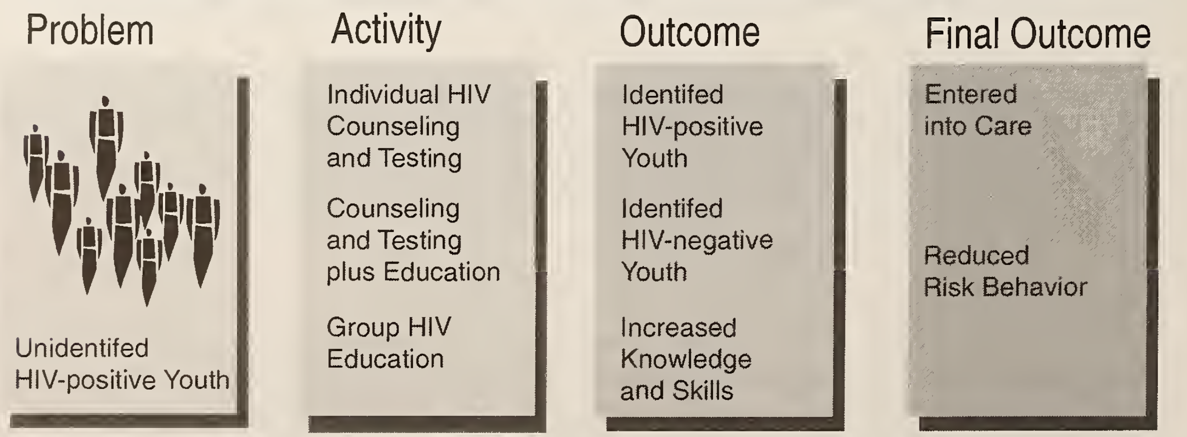
The program has three goals: (1) increase the number of youth receiving counseling and testing for HIV, especially those who were in high-risk situations, and thereby increase the number of HIV-positive youth aware of their serostatus, (2) use the HIV testing period as an integral component of an HIV intervention designed to reduce youth's risky behaviors, and (3) increase the number of HIV-positive youth entered into comprehensive medical and mental health services. These goals are pursued by developing a system of HIV case identification through use of community and school adolescent service centers, and with the participation of adolescent peer educators identified to work with targeted youth.

The educational sessions are conducted in groups and focused on HIV and sexually transmitted disease (STD) transmission and preventive skills, e.g., using condoms (and other safer sex practices) and cleaning drug paraphernalia. After each educational session, youth are offered individual HIV counseling and testing services using blood-draw procedures (switching to Orasure testing in 1999). While not all agencies are able to accommodate the program's educational sessions, all agencies utilize the program's HIV counseling and testing services. As part of the counseling and testing procedures, youth are assessed as to their personal risk behaviors, coping abilities and support systems. In addition, each counseling and testing session, including post-test counseling, are used as an opportunity for personalized HIV risk reduction education. Once an HIV infected youth is identified, they are assisted in transitioning to an adolescent-specific comprehensive health care clinic for early intervention and treatment. The project provides developmentally appropriate comprehensive HIV medical care, mental health care, nursing and case management.

Lessons Learned

Lesson #1: Outreach workers are difficult to hire and train.

CHRRPY wanted each outreach worker to represent several at risk populations of youth, have a college degree and have good writing abilities with knowledge of computers—especially with word processing. None of the



CHRRPY Model of Outreach and Transitioning Youth in to Health Care Services final panel of applicants selected for these positions possessed college degrees. The three applicants selected had extensive experience in performing outreach and HIV education, especially with youth. However, they lacked formal knowledge of adolescent development, had no certification in HIV counseling and testing, and two of the three applicants had no experience in phlebotomy. Formal phlebotomy certification required a six-month course sponsored by one of the community colleges. With this limitation, the director of the laboratory at CHRRPY organized his phlebotomy team to provide an intensive training program for the three outreach workers. The outreach workers also required orientation in body substance and infectious control, and Red Cross HIV counseling and testing certification. Finally, the outreach workers had to learn group facilitation and presentation skills for working with youth.

Presently, with the introduction of Orasure, the need for phlebotomy training is obsolete. However, finding adult providers who are youth sensitive, who can engage and encourage youth, and who can respect boundaries, especially in a work environment, are difficult to recruit and employ.

Lesson #2: Review agreements annually.

Turnover at the partnering agencies required renegotiation and re-establishment of letters of agreement with CHRRPY. One partnering agency did not replace a person critical to the function of the partnership, did not send out its workers to conduct street outreach as originally proposed in the letter of agreement, and did not respond to requests to meet to discuss resolution of these problems. Another agency lost its executive director, merged with another agency for survival and underwent a needs reassessment. This agency then became partners with another agency that provided services similar to those being offered by CHRRPY. Finally, a third agency was structured such that it was difficult to gather youth into groups for educational sessions. This agency moved twice over the period of the letter of agreement.

CHRRPY's contract with HRSA stipulates providing HIV counseling and testing to youth nineteen years and younger, however, most of the agencies linked with CHRRPY serve youth clients extending to age 24. These agencies were upset when youth over the age of 19 were denied the counseling and testing. The program was consequently modified to serve youth up to the age of 24. Another problem was that agencies generally opened for services around 4 p.m. and closed to the outside between 7:30 and 9 p.m. This left little time for the counseling, testing and educational programs of CHRRPY and required precise scheduling.

Lesson #3: To identify and help HIV-positive youth, gear the program for youth, not adults.

Focus groups of youth seeking services within the adolescent and young adult clinics reveal that youth who had previously consented to HIV testing in existing clinics for adults are unhappy with these services and identified the following issues:

- Providers are not youth sensitive and youth felt that they could not openly discuss issues that were key to them in engaging in risky behaviors. Further, youth felt that adult providers were critical of their lifestyles, ways of dressing and of their sexuality.

- Undocumented youth felt that existing sites did not allay their fears of being reported to INS for deportation despite seeking only HIV testing.

- Many sites are across gang territories and cannot understand youth's difficulty in returning for post-test counseling and test results.

- Many sites are open only during school hours making post-test counseling difficult to attend.

Case finding

The work of case finding and follow up is labor-intensive and costly. A constant process of engagement and stabilization of youth throughout all project services is key to transitioning youth into care. Youth identified in the community may require intensive manpower, intensive involvement by case finding and clinic staff for tracking these youth and for complying with their first clinic appointment. Some youth may require a number of phone calls, and direct face-to-face contacts in the community or at their homes before reaching their first clinic visit.

Youth who developed relationships with the CHRRPY outreach workers were more likely to enter into care than youth who were unknown by the outreach workers. Case finders report that developing an ongoing presence at assigned community agencies and engaging youth in discussions about topics beyond HIV 101 allow for an easier and more successful process of transitioning identified HIV-infected youth into care. Youth who are not previous clients of the community agency and who are new to all services are more likely to be untrusting of medical services when diagnosed as HIV infected. As such, a therapeutic relationship must also be tendered at the assigned agency by the case finder and the youth population.

Forming partnerships

Partnerships with community agencies with the goal of developing a citywide infrastructure to identify HIV-infected youth has been highly successful in getting youth into care. Youth agencies providing services to subcultures of youth (homeless, gay youth, school drop outs/pushed out; Latino youth, African-American youth, etc.) partnered with CHRRPY and sought CHRRPY services for their clients for HIV education, counseling and testing, referrals for adolescent specific primary care including STD screening and treatment, and mental health services.

Staffing with youth

The availability of youth peer health educators is a continual problem. However, since many youth clients are more receptive to prevention information when delivered by peers, having a youth organization and youth cab available as a pool of peer health educators is critical for continued project's delivery of services and continued development. Two peer educators were relieved of their jobs for failing to continue to perform according to their job descriptions. Other peer health educators were in school. With their school commitments and struggles with increased responsibilities in their lives, forming goals and future plans for themselves, not many youth peer health educators are available for educational sessions at the agencies. Also, some of the peer educators are HIV positive and dealing with life issues themselves. These life issues for both HIV-positive and HIV-negative youth might include being homeless, dealing with substances, engaging in unprotected sex during vulnerable moments and identifying with the very youth they are educating.

A pool of peer health educators is critical for continued... delivery of services...

Developing a youth peer health organization is critical for ongoing project services and project development. The project has helped to develop Chicagoland Youth Against AIDS, an organization of youth peer health educators reflecting youth from varied subcultures and organizations. This peer-led organization has provided a continued source of peer health educators, continues the outreach work of informing community agencies, schools and churches about HIV prevention services at CHRRPY, serves as CHRRPY's community advisory board, serves as a source of youth buddies for other infected clients, and helps with program development.

Leeson 3: Youth's perception of treatment differs from adults'.

Requirements of daily living take precedence over medication startup or medication adherence. Youth who live in unstable housing situations report that they could not consider starting medication. In fact, chart reviews reveal the worst treatment adherence among youth with unstable housing. Youth who have housing, food, clothing and mental health services are in better positions to consider medications long term.

Youth prefer no medications and worsening biological markers over medications with side effects and improving biologic markers. Even among the youth who are most active as advocates for themselves and who serve as role models for other youth, side effects of medications are likely to influence non-adherence and ceasing treatment, even when medications are shown to improve CD4 and viral load levels.

CHRRPY Chronology

October 1996

- Hire project manager and evaluator.

- Initiate evaluation protocol and instrument development.
- Initiate education protocol development.
- Notify agencies of award (six agencies).
- One agency lost due to misunderstanding of project budget.
- Create agency linkages and project plans (five agencies).
- Orient agency staff concerning CHRRPY (three agencies).

November 1996

- Begin interviewing for outreach worker/phlebotomists positions.
- Establish peer training protocol and quality assurance plan.
- Initiate agreement with laboratory for HIV antibody tests.

December 1996

- Peer educator recruitment initiated.
- Initiate the process of reaching formal agreements with agencies.

January 1997

- Hire outreach workers.
- Begin outreach worker orientation and training.
- Finalize pilot evaluation protocol and quality assurance plan.
- Formal phlebotomy training developed.

February 1997

- Start up project at two agencies.
- Begin data collection.
- Initiate weekly outreach worker meetings.
- Outreach workers obtain HIV Instructor Certification.

March 1997

- Start up project at one agency.
- Complete first agency interviews.
- Clarify and adjuste agency linkages and project plans (two agencies).
- Develop policy for adult employees who work with youth.
- Protocol developed for outreach worker to administer education and HIV counseling.
- Add Cook County Hospital as a testing site.

April 1997

- Adjusted HIV counseling and testing service protocol, extending age to 24.
- Outreach Worker Performance Evaluations initiated.
- Sign original letter of agreement with the Women and Children's Program at Juvenile Detention Center.
- Start up project at one agency.

May 1997

- Complete additional agency interviews.
- Assess pilot evaluation protocol and instruments.
- Assess education protocol.

June 1997

- Start up project at an additional three agencies.
- Finalize agreements with five of seven initial agencies and one new agency, evaluation protocol and instruments and education protocol.
- Establish quality assurance plan for education session.
- Host HRSA/SPNS site visit.

July 1997

- Develop intake form and buddy system for HIV positive youth.
- Develop system for re-contacting youth for follow-up and initiate first follow-up surveys.
- Developed data coding/entry system.

September 1997

- Finalize multisite evaluation protocol and instruments.
- Secure the services of a volunteer data entry person.
- Start data coding/entry.

October 1997

- Hire new outreach worker and two peer health educators.
- Youth peer role playing sessions developed.
- Outreach workers complete client centered training.

November 1997

Start up projects at an additional agency and site.

- Begin negotiations to provide HIV education and counseling and testing.
- Project evaluation and management team receive multisite data training.
- Develop peer education manual.
- Project evaluator enters into an official contract.

December 1997

- Develop linkage agreement with an alternative high school.
- Begin preliminary analysis on data.

January 1998

- Start up project at an alternative high school.
- Present preliminary findings at SPNS conference.
- Initiate new qualitative techniques into data collection efforts.

February 1998

- Start up project at an additional agency.
- Start negotiations with the State and City Health Departments to switch to Orasure for HIV testing.

March 1998

- Conduct two agency-collaborative role playing workshops for youth.
- Start up project at two agencies.

April 1998

- Conduct STD/HIV in-service educational program for participating agency staff.
- Start up project at two agencies.
- Youth hired as part-time data entry person.

May 1998

- Advise the City HIV Planning Council and the HIV Coordinated Care Committee on adolescent HIV issues.

June 1998

- Identify case management needs for HIV positive youth.

July 1998

- Start up project at citywide sites.
- HIV-positive youth invited to participate in video to teach high school youth about HIV/AIDS.

September 1998

- Develop a support group for HIV-positive youth.
- Develop an evaluation plan for the support group.

October 1998

- Conduct workshops for adult providers of HIV adolescent services.
- Conduct teacher workshops for the public school system.
- Conduct workshops for adult providers of HIV adolescent services.

November 1998

- Hire case manager for newly-identified HIV-positive youth.
- Formalize the primary care team approach for HIV-positive youth.

December 1998

- Outreach worker resigns.
- Identify need for additional training of all case managers.
- HIV positive youth participate as speakers at the Mayors World AIDS day.

January 1999

- Initiate search for outreach worker replacement.
- Reassign outreach workers to agencies until replacement are hired.
- Discontinue services at one agency and one of two sites at another agency due to low turnout.

April 1999

- Requestsupplemental resources to conduct survey and resurvey of youth.
- Coalition building with partner agencies begins.

May 1999

- Host conference on infrastructure building for adolescent HIV case finding among participating agencies.
- Project coordinator resigns.

June 1999

- Expand hours of service at one agency at their request.
- Initiate search for project coordinator replacement.
- HIV positive youth participate in *Living with Hope* video.

July 1999

- Initiate Orasure as method of HIV testing at all but one agency.

August 1999

- Develop the risk profile format for individual agency case studies.

September 1999

- Hire new project coordinator.

October 1999

- Begin orientation and training of new outreach worker case finder.

November 1999

- Participate in health fair sponsored by South Side Church.
- Conduct HIV/AIDS Conference through CHAMP alliance.

December 1999

- Terminate one outreach worker.
- Chicagoland Youth Against AIDS conduct role-playing at city-wide youth rally.

January 2000

- Adult outreach worker and youth peer educator assigned to Temporary Juvenile Detention Center to conduct education, counseling and testing.
- Hire youth as data entry person.
- Hire of outreach worker.
- Hire nurse to transition youth into care for CHAMP initiative.

February 2000

Hire case manager to transition youth into care for CHAMP initiative.

March 2000

- HIV-positive youth conduct workshops for Chicago Public School system.
- Conduct HIV/AIDS training workshops for outreach workers and youth peer educators.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the Chicago HIV Risk Reduction Partnership for Youth (CHRRPY), you are welcome to contact the project director and request technical assistance:

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Teen Outreach Project University of Miami (TOP-UM), University of Miami

Outreach Services to Medically Underserved Adolescents

Authors: Lawrence Friedman, Kimberley Shaw and Randall Sell

Introduction

Many sexually active teens who are at the highest risk for unwanted pregnancies and for contracting sexually transmitted diseases, are also the least likely to be receiving systematic medical care. Their under-utilization of primary care facilities may be due to a combination of circumstances. These include extreme poverty with associated lack of insurance coverage, absent information about or fear of traditional sources of medical care, ignorance due to youth, ignorance of health care providers and to the rights of minors to seek such services confidentially, estrangement from or absence of parents and psychological problems that may interfere with adequate self-care.

The Teen (Adolescent) Outreach Project of the University of Miami (TOP-UM) determined that one way of addressing the needs of at risk youth would be to offer free family planning and prevention services in the community via mobile van. By this means, youth would be able to access confidential health care without having to initiate the search for medical providers and without having to enter traditional, and perhaps unfamiliar, care-giving locations. The ultimate objective of the TOP-UM Project is to test and identify HIV-positive youth who were unaware of their HIV status, and enroll them in appropriate ongoing health care services.

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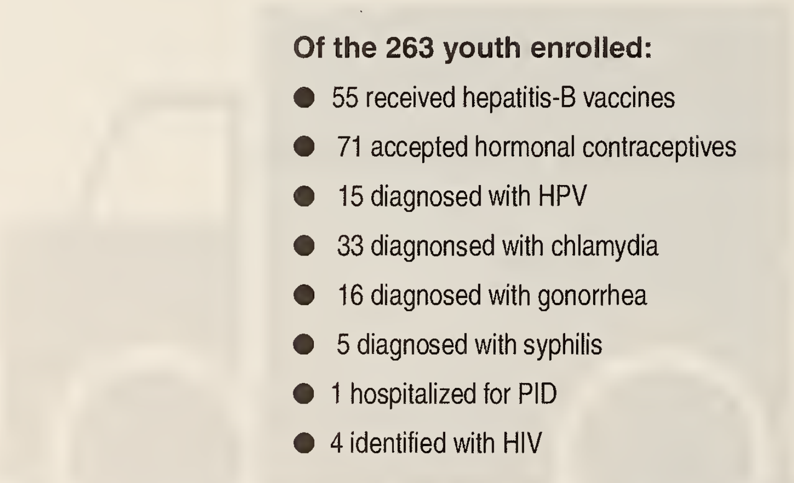
Location

TOP-UM is located in Miami-Dade County, Florida, an area that has a documented high rate of HIV infection. Because the greatest numbers of new AIDS cases are diagnosed in individuals who are 20-29 years old, it would seem plausible to expect to find a large number of HIV-infected 13-18 year olds. It was also would seem reasonable to expect that many of these youth are included in the group of persons who do not have regular sources of medical care and are unaware of their HIV status.

Services

Nontraditional means of accessing youth for sexual health services are important from both public health and clinical perspectives. TOP-UM is conducted in collaboration with the largest community-based social service and educational agency addressing HIV/AIDS issues in the county.

Preliminary canvassing of the city by a youth peer case manager resulted in locating a number of areas where poor, racial and ethnic minority youth congregate. Local HIV seroprevalence information was helpful to highlight specific areas to target. A mobile van travels to these locations, staffed with a physician or nurse practitioner, a psychologist, and two peer case managers. At the selected locations, the peer case managers provide both verbal and written descriptions of the project to interested teens.



Of the 263 youth enrolled:

- 55 received hepatitis-B vaccines
- 71 accepted hormonal contraceptives
- 15 diagnosed with HPV
- 33 diagnonsed with chlamydia
- 16 diagnosed with gonorrhea
- 5 diagnosed with syphilis
- 1 hospitalized for PID
- 4 identified with HIV

Youth are enrolled through the TOP-UM mobil outreach van and offered a wide range of sexual health services.

The staff members of the mobile van are equipped to offer a wide range of sexual health services beyond HIV pre- and post-test counseling and screening, including the distribution of condoms and literature for prevention education. Youth interested in the services being provided are offered tests for HIV, pregnancy, chlamydia, gonorrhea, syphilis and hepatitis-B, as well as genital examination and Pap smear. A psychological screening survey is administered and scored while the teen receives other services, so that crisis interventions and referrals can be made immediately.

All participants are given appointments to the medical center offices to receive test results. Those who qualify are offered the hepatitis-B vaccination series, and young women who desire family planning interventions are started on their choice of oral or injectable hormonal contraception. Females with positive pregnancy tests are referred to obstetrics services, while individuals with diagnosed sexually transmitted infections are treated according to public health standards. All services are provided at no cost to clients. Incentives for participation included tokens for mass transit transportation, meal coupons, movie passes, free interventions and condoms.

Lessons Learned

Lesson #1: Outreach health services are useful in reaching underserved teens.

It is possible to access medically underserved youth using a mobile van, under the conditions described above. Two hundred fifty-one participants, the number targeted for recruitment at the beginning of the project, were enrolled by midway through the second year. Eventually 263 subjects were included (55 percent female, 43 percent African American or Caribbean black, 33 percent Hispanic).

Service needs
Case finding in this way is likely to lead to identification of youth with needs for a variety of physical and mental health services. Fifty-five of the adolescents who participated in the project received hepatitis-B vaccines, and 71 accepted hormonal contraceptives (injectable and oral). The number of unwanted pregnancies that were avoided as a result of the project's outreach efforts is not known. However, the long-range employment difficulties of women who become single mothers as adolescents, and the educational and emotional deficits of children unwanted by single mothers, are well documented. Further, the project found 15 cases of HPV, 33 cases of chlamydia, 16 cases of gonorrhea, and five cases of syphilis. One female was hospitalized for pelvic inflammatory disease. Outreach to underserved youth is also likely to lead to the identification of youth who have both a very high level of need for psychological help and a willingness to accept services. Almost half (44 percent) of the participants in this project received psychological treatment as a result of their contact with the project.

Difficulty with follow-up
The project did encounter some difficulties with follow-up visits. Follow-up mostly did not occur in the van, but rather in the academic-based office setting. Staff time to track subjects was enormous, coupled with the transience of living situations for many of the youth. Two of the four identified HIV-infected youths were lost to follow-up.

> Many teens believe that they are invincible in general, and this may extend to a feeling of invulnerability to HIV infection.

Lesson #2: A mobile van may not be the best method.
Even in an area where HIV prevalence is relatively high among young adults, case finding of HIV-infected teens by using mobile van outreach efforts may not be successful.

Client-based reasons
Many teens believe that they are invincible in general, and this may extend to a feeling of invulnerability to HIV infection. Some of the most at-risk youth may therefore not recognize a need for accessing services at all, even if they easily accessible. Other adolescents who understand they may be infected, may be even more averse to exposing themselves to testing. By including psychological and family planning services, which are viewed as valuable from the adolescents' perspective, the reluctance to test can be reduced. It is also important to continually reinforce prevention information.

Other client-based reasons for the low level of case finding may include anxiety over accessing mobile health screening services, quite different than traditional health care encounters. Concern about the confidentiality of TOP-UM interventions for minors, as well as general lack of advertisement and knowledge about this new project, may be other contributing factors.

Systems-level reasons
On the systems level, the inability to find a sufficient number of appropriate youth venues, or at least those that would allow access to the most at-risk population, may contribute to the low level of case finding. It is also possible that HIV infection is not as common in this age group as anticipated, even in a relatively high seroprevalence area. Search for additional means of identification of HIV-infected youth in Miami-Dade County still is needed.

Lesson #3: Peer-based outreach services require intensive training and care.
Ongoing training and supervision requirements
The hiring, training and ongoing mentoring of the peer case manager outreach workers requires intensive

efforts and close monitoring by staff professionals. The amount of time needed for these functions is greater than anticipated. The information and skills required to operate in the field are extensive as are the protocols needed to guide peer-to-peer interactions. Training and supervision had to be ongoing in order to achieve a consistently high level of information sharing and to reduce the risk to both peer workers and the youth they target.

Potential risks to peer workers

The risk profiles of peer case managers often mirror those of the target group. Assuming a leadership role is not an inoculation against risk or vulnerability and the peer providers were in need of services. In some cases the psychological impact of working with an at-risk group required intervention by the mental health specialist on the project. With constant supervision these interventions could be made in a timely manner. TOP-UM supervisory staff developed a mentoring strategy that utilizes much the same approach as risk reduction strategies for youth. In this way more honest dialogues were possible with the peer workers about their own life conditions and relationships to risk. These conversations provide opportunities to strengthen the intervention overall and increased the peer workers awareness of potential risks in the target populations.

TOP-UM Project Chronology

No project chronology available.

Further Information and Technical Assistance

If you are interested in obtaining further information about the Teen Outreach Project University of MIami (TOP-UM) and the service delivery model, please contact the project director:

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Providing Age-appropriate HIV Service to Adolescents

Authors: Geri Botwinick, Walter Douglas, Robert Johnson and Robert Sember

This article chronicles some of the lessons learned from the DAYAM Project, a SPNS-funded program developed by the Department of Pediatrics at the University of Medicine and Dentistry of New Jersey (UMDNJ). The information is based on interim findings from the first three years of a four-year demonstration project.

Introduction

The Newark, New Jersey-based DAYAM Adolescent HIV/AIDS Project is a comprehensive, multi-disciplinary and developmentally-sensitive HIV/AIDS program designed to decrease the occurrence of initial HIV infections in youth between the ages of 13 and 25 and to overcome barriers to the early diagnosis and treatment of those who are HIV positive. In order to accomplish these goals, the program intervenes in the lives of both at-risk youth and those who are infected and in need of care. The project model is consistently youth-focused, the result of extensive work with both HIV-positive and HIV-negative youth in community and clinic settings.

The DAYAM model represents an ongoing mediation between ever-changing adolescent cultures and developments in the treatment of HIV/AIDS. While the project reflects the learning derived from extensive work with youth, fundamental challenges remain, such as the difficulty of identifying infected adolescents

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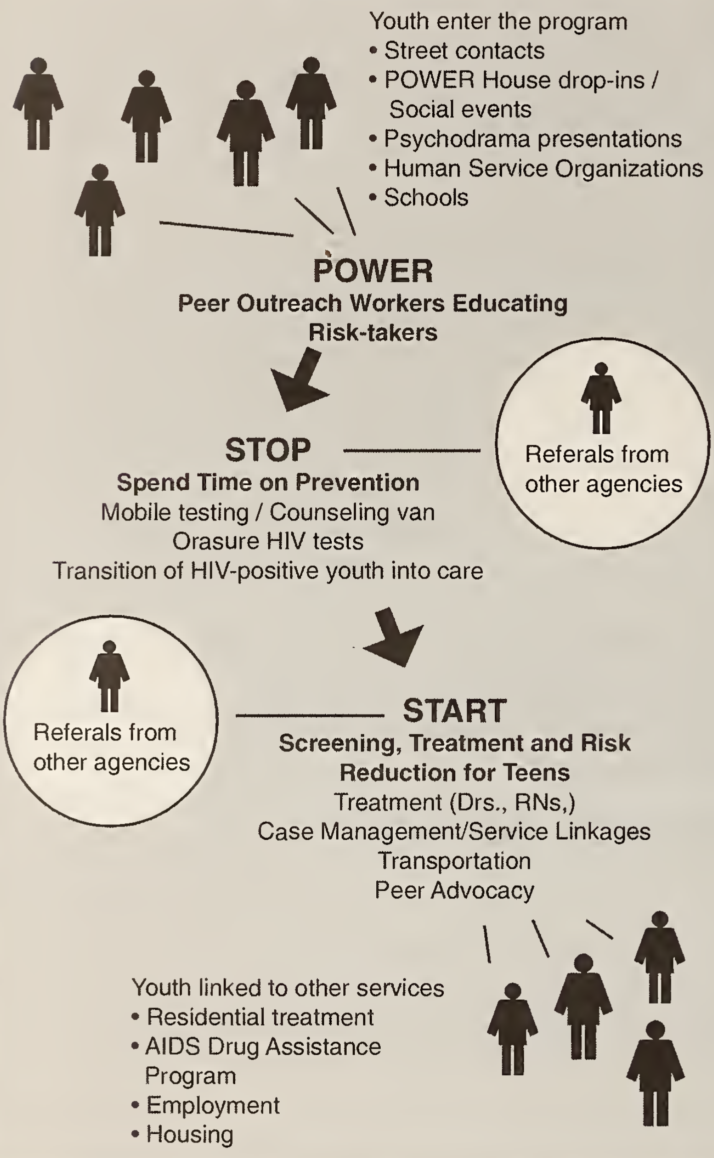
DAYAM model for continuum of care



who are either unaware of their serostatus or are aware but not in treatment. With the development of Highly Active Anti-Retroviral Treatments (HAART), new challenges have emerged. Ensuring adherence to the complex regimen and resolving the many life issues that characterize the lives of youth living with HIV/AIDS.

The following piece documents lessons learned by the DAYAM staff as a result of their case-finding efforts and their experience of the impact of anti-retrovirals on the lives of the HIV-positive youth involved in the program.

The DAYAM Project Model of Care and Services

Location

The service area for this project includes the four largest municipalities in the Ryan White designated Newark Eligible Metropolitan Area. Together, these municipalities constitute the urban center of Essex County, the second most populous in New Jersey. The majority of the almost half a million people in the project's service area are African American (66 percent). Whites and Hispanics/Latinos account for 24 percent and 9 percent respectively.

The project is located at the UMDNJ University Hospital in the city of Newark. A city with a rich history, Newark has been troubled in recent decades by overwhelming economic difficulties and widespread social ills. Multiple generations of city residents have lived and continue to live in poverty. Crime rates are well above the national average and drug use is widespread. Newark and Essex County now add to that list, the distinction of being the epicenter of the AIDS epidemic in New Jersey.

Although Newark is home to only four percent of New Jersey's general population, it represents 19 percent of the state's cumulative cases of AIDS and 22 percent of the HIV infection reports. And while Essex County accounts for less than 10 percent of New Jersey's population under 20 years of age, it accounts for 32 percent of reported AIDS cases and 34 percent of HIV infections reported among New Jersey youth between 13-19 years of age. Given the latency period of HIV, it is likely that a significant number of those between 20-29 years of age who are reported to have HIV/AIDS were infected during their adolescent years.

Program Model and Services

The DAYAM program is designed to provide services that span the adolescent HIV/AIDS continuum, including prevention, access to counseling and testing, transition to clinic-based care, and state-of-the-art medical and supportive services using case management, counseling, and peer advocacy to transition youth across the continuum of care. The program model consists of three major components:

1. POWER (Peer Outreach Workers Educating Risk-takers) A peer outreach program which employs high-risk peers to provide street contacts, social events and psychodrama presentations to thousands of adolescents each year, in addition to handing out educational materials and condoms. Between January 1998 and December 1999, more than 3,500 adolescents were reached during street contacts alone.

2. STOP (Spend Time on Prevention) A mobile van provides HIV testing, including pre- and post-test counseling. POWER workers often accompany the van to provide outreach in areas popular with high risk groups. In 1998 and 1999, 881 adolescents were tested.

3. START (Screening, Treatment and Risk Reduction for Teens) HIV-positive youth are transitioned by a STOP counselor and a START case manager into treatment at START. Since the initiation of SPNS funding in October 1996, a total of 33 new HIV-positive youth have entered the START program. Before the SPNS enhancements were funded, the START program consisted of medical staff only; the program did not have case managers or peer advocates.

Provider Teams

The teams assembled across the three project components are made up of both adult professionals and youth peer workers. Medical care is provided by pediatricians and licensed nurses with other specialist medical care available through UMDNJ's University Hospital. Experienced case managers assist with the management of care and help access ancillary services. Outreach workers and peer leaders guide a large cohort of peer educators. Peer advocates are also specifically trained to work with youth who are HIV positive or living with AIDS. Administrative staff are as much a part of the team as anyone else, providing crucial assistance managing this multi-component project. The integration of all levels of staff into strongly bonded provider teams increases the effectiveness of the model overall. Equally important, are the close relationships between professional staff and peer workers which ensure a youth friendly tone for the project while also constantly enhancing the knowledge and skills of the youth.

Lessons Learned

POWER, the outreach component of the DAYAM Project, has developed highly effective methods for reaching large numbers of youth engaged in high-risk behaviors and providing them with crucial information and resources for preventing HIV infection. In conjunction with the STOP team and the outreach van, many of the youth approached in the community have accepted HIV testing and have participated in pre and post-test counseling which further reinforces the risk-reduction information shared by the outreach workers. The success of the program is due in large part to the way in which the project works with peers workers. The introduction of the Orasure HIV test led to an increase in testing rates. The lower than expected identification of infected youth has raised questions about the prevalence of HIV in the community and prompted an expansion of outreach activities.

Lesson #1: Challenge youth to reduce risk.

Simply being from the targeted communities is insufficient for youth to qualify as peer outreach workers in the program. The POWER outreach activities are built on the foundations laid by an intensive intervention into the lives of at-risk youth who become peer outreach workers. That is, peer workers are challenged to reduce or resist risk behaviors prior to going out into the community and urging others to do the same.

Before working with others in the community, the youth selected for the POWER program are involved in a program of activities intended to impact critical behavioral and psychological issues that increase the likelihood of their engaging in high-risk activities. These include low self esteem, family stress, poverty, racism, and peer pressure to become sexually active, smoke and use drugs. Through the program, youth are integrated into a social support network that reinforces the risk-reduction messages of the program. The POWER staff, young adults from the community and alumni of the program offer positive role models and a mechanism for linking youth in crisis with supportive services. Youth involved in the POWER program experience psychosocial and developmental gains from their participation in the program. They learn to value school and work and as they transition to other employment or academic activities they increasingly rely on the POWER staff for guidance and assistance.

While the POWER training shapes the peer workers, the youth have, in turn, shaped and strengthened the program. Reflecting on their own experiences, the POWER youth have underscored the efficacy of peer street outreach. As representatives of a number of adolescent sub-populations and cultures (e.g. pregnant youth, youth with histories of STDs), they have been able to target other members from these groups. In the field they work as a team, ensuring that members of the team are matched with youth encountered in the community. Peers from subpopulations or subcultures are more familiar with the sites of youth congregation and operate more comfortably and easily in these settings. Finally, they are also familiar with the idioms and in-group language of these subpopulations.

Lesson #2: Establish a presence.

To back the peers, the POWER and STOP teams ensure that the presence of the DAYAM Project is reinforced in other ways. To build an on-the-street profile, the outreach van is distinctively marked and regularly returns to the same location. The distribution of risk reduction kits, tee shirts and other items that identify the POWER team increases acceptance of the project and ensures that the message lingers after the peer outreach workers and the van have departed.

Through these multiple messages, members of the community are also informed of the DAYAM Project's other services. Those contacted on the street often enquire about ways of accessing DAYAM services not immediately available in the field. Many of the youth request a telephone number to anonymously access information and testing. Future POWER team members are also recruited through these street contacts. As a result of the street encounters, the project staff learned that it often takes several contacts with an individual to establish the trust and comfort required for the individual to engage in a detailed conversation about risk factors and to accept the offer of an HIV test. The consistent presence of the van and the project message is important to building individual and community acceptance and trust.

> Peers from targeted populations are familiar with sites where youth congregate, integrate easlily and use the in-group language and idioms.

Once a young person has accepted the offer of an HIV test, steps are taken to ease the testing process. Counseling sessions before and after testing are youth oriented, focusing specifically on adolescent psychosocial issues associated with HIV. A case aide establishes a method to confidentially contact the young person in the event she/he does not return for the test results. These include recording telephone numbers, addresses and favorite sites for congregation, trusted friends and relatives.

STOP staff found that one of the greatest barriers to testing was fear of the needle. The advent of the Orasure test was the most effective solution to this barrier. As word of this alternate testing method spread among the youth, there was a noticeable increase in the willingness to be tested. The success of the Orasure method demonstrated unequivocally that this is a viable, if not superior, method for testing members of the at-risk youth population.

Lesson #3: Outreach stretches beyond targeted populations.

Despite contacting thousands of youth and testing hundreds, the number of new cases identified was surprisingly low. One adolescent was identified through testing compared to 38 infected adults tested during the same period. Staff on the STOP van were, however, consulted by five youth who had either known they were HIV-positive and had never sought treatment or had been in treatment but dropped out of programs. A number of HIV-positive youth were referred to the START treatment program by local churches, human service organizations and other hospitals or they heard of the program by word-of-mouth.

Two lessons were derived from these outcomes. The first is that when conducting street outreach, information about the program reaches beyond the target population. As a result of the outreach van's high visibility, community-based organizations and city and state institutions learned of the program and referred clients into the program. This inadvertent institutional outreach proved very beneficial for the project and has been made a component of the outreach effort.

How do the Youth Identify?
Of the 38 HIV-positive youth in the clinic between 1993-1998:

- 19 gay or lesbian
- 3 transgender
- 1 pregnant
- 11 parenting
- 4 in commercial sex work
- 90% African American
- 10% Latino/a

The second lesson is that the initial outreach plan was not accessing groups in which HIV infections are concentrated. As the director of the DAYAM project has observed, in order for infection to occur, it is necessary that both risk behaviors and the HIV virus be present. Surveys of youth reached during outreach clearly indicate that they are a high-risk group in need of prevention programming. Fortunately, the virus does not appear to have been introduced to these groups.

Infections are not uniformly distributed across a population but follow routes determined by social and behavioral networks. The infected youth in care with the START team provide a profile of what these networks and sub-populations are. The project initiated a number of activities to increase access to these networks by developing outreach for specific sub-populations, including young women who are or had been pregnant, youth with histories of STDs, LGBT youth, sex workers, and Latino/a youth.

To enhance access, two strategies were adopted. The first was to partner with other agencies that targeted specific subpopulations. Part of the counseling and testing outreach is now conducted in collaboration with Covenant House which serves runaway youth and youth involved in sex work/survival sex. Project Fire, serving gay and transgender youth has been approached to develop a similar collaboration as have community youth programs that have significant Latino/a populations.

The second strategy has been to conduct outreach in new areas and at late night hours. This is specifically targeted to youth who are involved in commercial sex work, are homeless and are drug users. For these populations, the visibility of the van may be a barrier and outreach workers are using different tactics to develop a presence on the street that will not draw attention to the youth.

Lesson #4: Develop and maintain adherence.

The START treatment team helped the youth in their care achieve an 85 percent compliance rate with appointment keeping and a 70 percent compliance rate with medications. These successes may be attributed to changes in the medications and the structure of the program.

Changing medications

The majority of problems with medication adherence resulted from the therapies themselves. The number of pills required in each dose and the frequency of dosing was a burden on the youth and interfered with daily routines (school, work, etc.). The youth also feared that their HIV status would be revealed if others became aware of what medications they were taking. Consequently, they chose not to take the medications when at school or at work.

The introduction of combination Nucleoside Reverse Transcriptase Inhibitors (Combivir) decreased the number of pills per dose while the reduction in the periodicity of dosing for an additional protease inhibitor (Viracept) significantly improved the quality of living of many clients. The frequency of clinic visits decreased, there were fewer admissions and few visits to hospitals for emergency care.

Psychosocial barriers to adherence
Mental health issues, family problems, difficulties obtaining childcare, social issues such as peer pressure, and problems with public transportation were greater contributors to medication and appointment compliance than anticipated. A number of the youth were diagnosed with depression and experienced overwhelming stress because of family conflicts. Young mothers were reluctant to bring their children to clinic with them and had difficulty arranging childcare when needed. The youth also experienced their HIV-status as a barrier to their full participation in the activities of their social groups which are made up predominantly of non-infected youth. Taking medications only reinforced this sense of difference and exclusion. Finally, the public transportation system in the city is inconvenient, particularly for youth who are ill. Many lack the finances to pay the expense of transportation.

> Medication and appointment adherence is more difficult for clients with mental health issues, family problems, child care needs, transportation difficulties and social issues such as negative peer pressure.

Each barrier had to be addressed by project staff. Through counseling and support from fellow patients, youth have been able to reduce the negative impact of mental health and family issues. Issues of shame and difference have also been addressed through counseling and peer support. Case managers have helped alleviate problems with transportation by providing vouchers and rides with UMDNJ vehicles. Childcare linkages have been made with relatives and public programs.

One of the most useful changes to the project was an expansion of the one-stop shopping model to mean not only that most if not all services are available in one place, but that they are available at the same time. Noting that appointment-keeping compliance is inversely related to the number of appointments, the entire START team is available during clinic hours. This reduces the need to make multiple appointments and reduces the disruption of school and employment schedules.

Peer advocates and support groups
The DAYAM project has developed into a significant social support network for HIV-infected youth through the increasing use of peer workers in the treatment environment. As with the use of peers in the POWER and STOP components of the program, this benefits both the youth selected as peer workers and those they serve.

Three years ago an HIV-positive client in the program was hired as a peer advocate to assist the case managers escort and link youth to needed services and to remind them to take their medications. As a result of the success of this first peer advocate, three more were hired with the assistance of Title 1 funding. In addition, a case aide position was established as a career advancement for the most effective peer advocate. These positions helped build the self-esteem of the youth who were selected to fill them while also giving the youth a greater input into the running of the program. The result was a marked increase in involvement, trust and self acceptance. For example, a number of the youth

Among the DAYAM clinic population of HIV-positive and HIV-negative youth:

Sexual activity

Sexually active	70%
Use condoms consistently	33%
Have had at least one STD	54%

Among sexually active females

Pregnant at least once	27%
Report sex with significantly older partners	33%

Drug use

Drink alcoholic beverages	49%
Smoke marijuana	30%
Use crack or cocaine	9%
Use heroine	3%
Have taken intravenous drugs	2%

who had been clients in the program for some time came out as gay. They had originally presented themselves as heterosexual because they feared being ostracized by others in the program.

The peer advocates also revitalized the program's attempts to convene support groups. The advocates invite fellow patients to attend the groups, they plan agendas, enlist speakers, and advertise the programs. There is now one active group that averages at least 10 attendees. The peer advocates have also helped to create a peer culture within START that supports adherence to medications and keeping medical appointments.

Lesson #5: Support normal life activities.

The use of anti-retroviral therapies has significantly improved the quality of living of many of the youth in the START program. Their medical needs have been reduced as evidenced in fewer visits to the clinic and fewer hospital admissions. Yet the youth are making more frequent and longer visits to the nursing and case management staff for assistance with their ancillary service needs, the needs associated with surviving HIV infection and being more involved in normal life activities such as school and employment.

Emerging needs

The youth are requesting a range of services that go beyond the scope of direct medical intervention. Aware that sustained good health requires a holistic approach to the youth, START staff are working to meet these needs which include: mental health services for clients and family, academic remediation, job training and job placement, transportation, nutrition counseling and access to alternate therapies, and childcare.

The need for mental health services has greatly increased. As both the infected individual and the family adjust their understanding of HIV as something that youth can live with rather than as a death sentence, existing personal and family stresses emerge more strongly. Clients have presented with depression. Behavioral problems such as impulsive and aggressive behavior have also needed to be addressed. To accomplish this, mental health professionals are being integrated into the START team.

Case management

Case management services are being used more extensively by more of the youth. Case managers assess each adolescent's individualized needs in all areas of daily living, including housing, financial assistance, family and partner relationships, school and employment, substance abuse, mental health, parenting and child care. The case managers, assisted by the peer advocates, are the glue that holds the system together for START patients. Transportation and food vouchers are often provided. Concrete survival needs such as stable living arrangements and food are addressed first, so that they are not barriers to medical care and medication and appointment adherence. For other service needs, such as housing and employment-related services, START patients are linked to community resources.

Scheduling appointments

As medical treatment takes up less of their time and they become more involved in life activities, the youth have requested the opportunity to receive services at times that do not interfere with either school or work activities. This means there is a greater demand for evening and week-end clinic hours. Evening and Saturday hours are now available.

DAYAM Project Chronology and Timeline

October 1996

- Advertise three new budgeted positions: a nurse practitioner, case manager and program assistant. The case managers tracks HIV-positive youth identified through testing and eases their transition into treatment. The nurse practitioner augments clinical services.

December 1996

- Outreach to Newark schools for in-class program; no responses.

- Focus groups held to review and make suggestions regarding outreach methods to enhance and encourage HIV testing.

- Latina program assistant added.

January 1997

- Institute regular monthly meetings for all DAYAM's HIV programs to facilitate inter-program communication and continuity of care. Discuss successes, problem-solve, share information on client needs, multi-site collaboration, new initiatives, and grant opportunities. POWER outreach slowed by winter weather; focus more on presentations and school-based work. Staff all take case management training.

May 1997

- Begin Orasure (saliva testing) on STOP van. State Department of Health supplies STOP with 50 Orasure tests per month.

June 1997

- Case aide is hired to assist with case management functions; caseload consists of clients with less complex needs. Housing and food are paramount to clients.

- Combivir (AZT and Epivir) prescribed to START patients. Enables clients to take combination therapy in less doses, with fewer pills, thereby facilitating treatment adherence.

- Decision made to hire nurse coordinator rather than nurse practitioner. Search for candidate begins.

September 1997

- POWER plans "Let's Talk Month" at a local high school; involve teachers with buttons, manuals, etc in educating students about risk behaviors, STDs, HIV. Local middle school efforts going well; POWER co-facilitates four health classes one day a week.

- Efforts continue to collaborations to increase testing/identification of homeless youth; STOP to do HIV testing on-site.

- Still receiving 50 Orasure tests from the State DOH per month; need approximately 250 per month.

- Still trying to negotiate a collaborative agreement with Project Fire (sponsor of houses for transgendered and MSM youth) as well as with Integrity House (substance abuse program).

November 1997

- Nurse hired to function as patient care coordinator to track patients' lab tests, follow-up, specialty referrals, etc. Full interdisciplinary team now in place.

December 1997

- START averaging two new patients per month mostly referred by other agencies. "Shout outs" for medication adherence and appointment compliance started every Thursday.

January 1998

- Emergency cash assistance identified by case managers as essential for clothes, bridge fund for medications, personal hygiene products, etc. Apply for funding through Title I application.

February 1998

- Caseload assignments for case managers now at 24 active clients each.
- Patient's family is assisted/linked to services as needed. Title I award includes additional medical care dollars, as well as case management, and direct emergency services (including dollars for prescriptions and transportation).

May 1998

- Program expands START team to include bilingual medical assistant.
- First peer advocate hired.
- One hundred-fifty more youth than last year at this time, are tested—largely due to Orasure.
- Counseling group has five clients. Previously had problems getting youth to attend because of privacy/disclosure issues.

June 1998

- Emphasize need for late hour HIV outreach/testing and counseling, particularly for sex workers, transgendered, homeless teens, and Latinos.

August 1998

- Case managers, peer advocates, medical assistant, RN, data coordinator and others now co-located, facilitating communication regarding clients.

May 1999

- The program gets so many requests to do presentations statewide that street outreach is suffering.
- Decision made to divide peers into two teams; one will focus on street outreach; the other will do psychodrama presentations.

August 1999

- Title I funding enables expansion of peer advocate positions to four slots. Three new peers hired, two males and one female.

September 1999

- As clients feel better, doctor visits decreased while visits to other team members (nurses/case managers) increased significantly. The program definition of "appointment compliance" is modified to reflect this.

January 1999

- Ongoing efforts to recruit more Latinos in coordinator and/or outreach positions in effort to change community image of program as being African American-focused.

November 1999

- Video on DAYAM's HIV programs completed. To be used for marketing to community, to potential funding sources, etc.

December 1999

- Continue to receive funding from Ryan White Title I to maintain expanded peer advocate component with three additional male and female peers and will promote one peer advocate to case aide position as a career ladder move.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by the DAYAM Project, you are welcome to contact the project director and request technical assistance:

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SafeSpace, Center for Children and Families

Providing HIV Prevention and Services to Homeless Youth

Authors: Carl Siciliano, Lynn E. Walker and Jo L. Sotheran

Introduction

Homeless or street youth are an overlooked subpopulation in HIV prevention and services. Even their numbers are not accurately estimated, and there are few programs to serve them. SafeSpace has developed an innovative and comprehensive program to meet their complex needs, including mobile outreach, comprehensive assessment and treatment services and housing.

As a result of their dysfunctional backgrounds and later experience on the streets, homeless teens are generally distrustful, suspicious of any type of authority and service, emotionally volatile, and slow to develop trust. Linking these individuals to any type of services, especially medical, HIV, mental health, or substance abuse services, first requires meeting basic needs for food, clothing, shelter, personal hygiene, and community. SafeSpace's programs seek to provide a continuum of care, to first engage youth and build trust, then to provide them with needed housing and services. This continuum includes several major components, ranging from relatively casual and basic interactions with youth to comprehensive residential services.

The project has learned a number of instructive lessons on how to work with homeless youth, build trust and allow access to services. A brief overview of the project as well as a discussion of three critical lessons are highlighted here.

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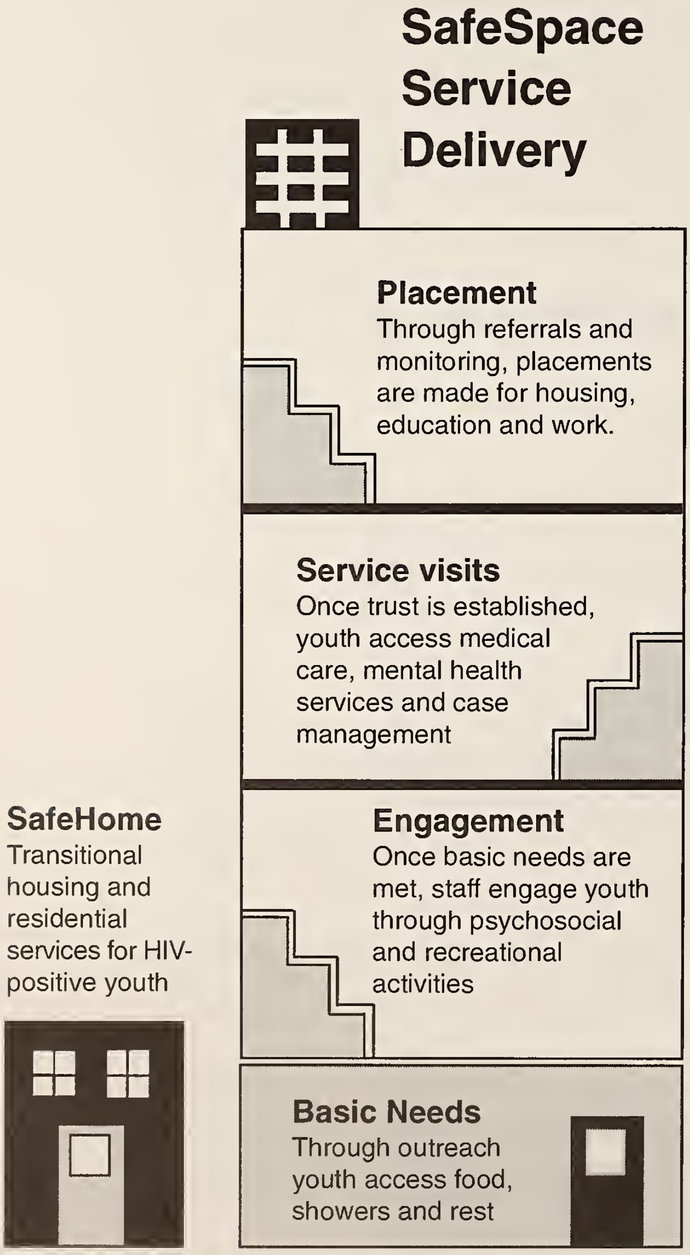
SafeSpace Model of Care and Services

Location

Despite the lack of concrete numbers on population size, there is little doubt about the magnitude of the needs. Most of these individuals come from backgrounds of childhood sexual, physical, and/or emotional abuse. They originate in the same impoverished neighborhoods and families that produce many adult AIDS cases. Most are psychosocially unequipped to use New York City's adult homeless services system, and the 30-40 percent who are gay, lesbian, bisexual, or transgender must cope with additional barriers to services and acceptance. With little education and few employable skills or eligibility for benefits, many turn to survival sex, often supplemented by intense drug use and sales, to subsist. They often engage in activities that put them at high risk for HIV and other infectious diseases, but cannot access or do not trust the existing facilities for prevention, testing, and medical care. Few are able to succeed in even the few residential facilities for homeless adolescents because of their serious psychosocial deficits and damaged interpersonal skills that are produced by life on the streets. SafeSpace, part of the Center for Children and Families, is one of the few places they can turn.



SafeSpace Service Delivery

Placement
Through referrals and monitoring, placements are made for housing, education and work.

Service visits
Once trust is established, youth access medical care, mental health services and case management

Engagement
Once basic needs are met, staff engage youth through psychosocial and recreational activities

Basic Needs
Through outreach youth access food, showers and rest

SafeHome
Transitional housing and residential services for HIV-positive youth

Outreach
Staff goes to the youth by street, van or institution

Services

Transitioning youth into care often involves numerous contacts over many weeks with "Mobile SafeSpace." This is a fully-equipped motor home configured as an outreach unit. It brings food, clothing, shower facilities, counselors, and HIV testing to young people on the streets, and transports them to safe and emergency shelter as needed.

The outreach staff includes a team of social workers, counselors, and peer educators. They travel through the five boroughs of New York City on a regular schedule, making contact with youths in the very early morning and late night in areas where the young people congregate. Many street youth are resistant to services, distrustful, and reluctant to come to the SafeSpace central Day Center in midtown Manhattan. Mobile SafeSpace works to connect these youth with necessary services as much as possible on the spot while gradually coaxing them into the wider array of services at the Day Center.

The main area of SafeSpace's programming is the Day Center, a 24-hour, seven-day-a-week assessment and service center. It provides a comprehensive constellation of services offered on-site by its own staff, who become familiar and trusted figures to program participants. These services include low-threshold basic needs (showers, laundry, clothing, meals), medical care (primary care and HIV-specific prevention education, counseling and testing), mental health services, case management, substance abuse prevention and treatment, peer counseling, pre-employment, GED and life skills training, recreational activities, and housing placement assistance and advocacy.

Residents of SafeSpace also use the Day Center's services. Facilities currently include:

- Short-term emergency shelter in the SafeSpace Day Center dorm, available immediately by referral from the outreach units, with transportation provided by the outreach staff if needed. Maximum stay is three nights.
- SafeHaven, a series of scattered-site apartment shelters, provides temporary emergency housing in home-like environments, and prepare the young people to move on to more permanent housing. Maximum stay is six months to one year.
- SafeHome is one of the nation's first transitional housing programs for homeless adolescents who are HIV positive. This 18-24 month program provides 24-hour support and structured supervision in a home-like environment for 12 male, female, and transgendered youth. Young people are provided with an HIV/health management system that enables them to take positive steps to promote and preserve their health. An aftercare program prepares residents for the transition to independent living, and provides ongoing support services after the transition.
- A transitional residence focused on serving gay, bisexual, and transgender street youth, is currently in development. Those groups are at greatest risk of HIV and other infectious diseases on the streets, but they also have the greatest difficulty accessing mainstream youth services because of their sexual minority status.

By providing a comprehensive array of supportive services to clients in a variety of housing settings within the agency, SafeSpace makes it possible for youth to make connections with needed services within a supportive community and to develop a personal support network of peers and staff members. Within this environment, youths are encouraged to seek information, testing and assistance while making use of other program services and resources.

HOPWA funding is not being used directly for housing. SafeSpace's housing continuum is funded through a series of private, state, and other federal sources. The HOPWA program covers specialized services, most coordinated through SafeSpace Day Center, designed to stabilize and transition high-risk youth into finding and maintaining independent housing and productive life.

Information

Many clients in need do not even know of the availability of programs like SafeSpace. An institutional outreach program publicizes the availability of SafeSpace's services and programs in a variety of venues where youth in need are found.

Conflict resolution

Poor interpersonal skills (difficulty resolving conflicts and expressing disagreement respectfully) are a common after effect of the stresses of street life, and is a serious impediment in education, employment, or group living situations. A mediation specialist, to be formally trained in mediation techniques, will offer workshops and individual conflict-management training, as well as individual and small group consultations as needed.

Housing placement and advocacy

Adequate housing is the most basic need among homeless youth. However, their lack of resources, combined with psychosocial deficits, makes accessing and maintaining residence in the few existing facilities a difficult task. A housing specialist assists program members in locating and navigating the service system for housing and income benefits, and serves as an advocate when needed. The specialist also carries out a structured program to prepare SafeHome residents for independent living, and coordinates follow-up aftercare services for those who have already made that transition.

Psychological services

The prevalence of abusive backgrounds means that mental health problems often hinder street youth in adapting to the already formidable tasks and routines of independent life at a young age. A mental health specialist, a CSW, facilitates therapy and support groups at SafeSpace, provides individual supportive psychotherapy, as well as evaluation and referral to other providers, including SafeSpace's in-house psychiatric consultant.

Substance abuse prevention and treatment

Drug and alcohol abuse, often at serious levels, is a common adaptation to the stresses of life on the street. It impedes access to and progress in housing, education, employment, and relationships. To address this need, a substance abuse specialist facilitates substance-abuse groups at SafeSpace and SafeHome, provides consultation to other staff, does individual evaluations, and refers to more specialized outside facilities as necessary.

Youth-friendly HIV services

Despite their high risk of infection, street youth do not usually take advantage of HIV testing. Once basic needs are met and a basic support network is in place, youth may be more inclined to consider HIV testing. An in-house "Living with HIV" program provides HIV testing and counseling in a supportive atmosphere (coordinated with the in-house primary care clinic), but also can refer to and coordinate care with other services. The program also offers support groups and counseling for the diagnosed.

Lessons Learned

Lesson #1: Be selective.

A large proportion of SafeSpace's participants has serious substance abuse problems. Although staff had long recognized this problem, providing for treatment needs proved unexpectedly difficult. Initially SafeSpace had planned to contract with a large substance-abuse treatment provider, known for both its homeless-services programs and attention to HIV prevention and services. However, SafeSpace found that the provider had little experience with or understanding of adolescents, and did not seem to recognize the special concerns of gay, lesbian, bisexual, and transgender clients. Finally, the provider's approach emphasized a therapeutic community model. With its emphasis on confrontation, this model seemed unsuited to SafeSpace's multiple-problem clients with their frequent history of abuse, emotional trauma, and extreme suspicion of authority.

Service providers for multi-problem populations must recognize that specialized expertise is of little use to clients who will not use these services.

SafeSpace then sought out one of the few substance-abuse providers in New York with experience treating adolescents. Although this provider's general approach seemed more compatible, its program was oriented to relatively mainstream adolescents, and it had little or no understanding of homeless populations, much less homeless adolescents.

Lesson #2: Sometimes in-house service is better than referrals.

Service providers for multi-problem populations must recognize that specialized treatment expertise is of little use if clients will not use it. The ability to engage should be the first priority. Eventually SafeSpace decided it should guarantee knowledge of its population by housing its basic substance abuse facility within the agency, referring out when necessary for specialized services such as detoxification. While finding an appropriate staff member was time-consuming, the results have been excellent.

A substance abuse specialist with credentials (New York State Certified Alcohol and Substance Abuse Counselor) has been added to the SafeSpace staff. Dividing her time among the components of the SafeSpace continuum, the counselor conducts the substance abuse groups required by SafeHome's licensing as a drug treatment residence. At SafeSpace day program, she conducts groups and is available several hours a day for informal counseling and casual visits that often engage youth into more formal counseling for their drug use. The specialist serves as a liaison and specialized resource for appropriate outside referrals. Finally, she provides informal consultation and education to staff of all the SafeSpace programs on issues related to substance abuse. This in-house primary substance abuse treatment has allowed SafeSpace to offer treatment that is both adapted to the special needs of its clientele, more easily accessible, and more integrated with the rest of SafeSpace's programming than could be achieved by a program composed entirely of off-site referrals.

Lesson #3: Clients need to maintain achievements therefore follow-up is critical.

Homeless youth enter residential programs such as SafeHome with deficits that make maintaining housing stability difficult. Most SafeHome's residents (all HIV positive) do well while in residence: their psychosocial functioning improves at the same time that adherence to medical regimens is increased by the presence of nursing staff. Staff monitor medications, educate the residents on treatment, carry out minor treatment in coordination with and provide liaison to residents' personal medical providers. This superior adherence is reflected in stabilization of their medical conditions as well as positive feedback from individual residents' HIV-specific medical providers.

> Transitional and aftercare programs are required to help youth move from the agency residence into an independent living situation.

However, many residents decline once they leave SafeHome for independent living situations. There is a two-year limit on SafeHome residence, but some residents choose to leave earlier. Once their medical condition deteriorates sufficiently to yield a CDC-definition AIDS diagnosis, they become eligible for independent housing placements subsidized by the NYC Human Resources Administration's Division of AIDS Service and Income Support program for people with diagnosed AIDS. Many take the opportunity for totally independent living. Unfortunately, they are not always ready for it and without the social and medical supports offered at SafeHome, fall back into old lifestyles and deteriorate medically when adherence to medical appointments and regimens is no longer supported. SafeHome became aware of the depth of the problem when it began receiving calls from former residents' physicians, attempting to locate them for missed appointments or to report poor lab test results.

SafeHome has created a transition and aftercare program, managed by its housing specialist. The specialist and resident jointly plan for departure and independent living, as part of a structured 10-part transition cycle program. The specialist may participate in the search for appropriate housing placement along with the resident. Finally, all departed residents are contacted regularly on a scheduled basis for several months after departure, to ask if there is anything they would like additional help with, and reinforce the message that SafeHome is always there should they need to talk to or need help. A large number of residents have participated in the aftercare program. It has generally been well received; many residents come back to visit and stay in touch.

Lesson 4: One-stop service is effective by reaching the most difficult to serve.

Experience with multiply diagnosed populations and particularly with adolescents, suggests that service engagement and adherence are much improved when youth develop a consistent relationship with providers, and have as many services as possible available under the same roof. Achieving this goal is even more difficult than it first appears, especially when new services and initiatives must be integrated into an existing program. Results are not likely to be seen immediately, as they are the product of multiple adjustments of a program of multiple components.

> A lengthy period of low-level contacts is necessary... Thus, programs relying on outreach to multi-problem populations may not see the fruit of that outreach for some time.

SafeSpace focuses on those most at risk. They are, unfortunately, the least likely to present themselves, the most difficult to find initially, and by far the most difficult to engage. The highest risk youth are often gay, bisexual or transgender, and are most likely to engage in high-risk survival sex for either shelter or money. Their past histories of emotional, physical, and sexual trauma (often related to their sexual orientation) combined with their current emotional instability, heavy drug use, stigma and depression, conspire to make them intensely suspicious of authority and services. Their reliance on street sex work makes them difficult to locate because of their irregular hours and the unpredictable pressures of law enforcement.

Service engagement consists as four overlapping stages: 1) initial: first, often casual, contact; 2) repetitive: repeat visits, often low level but establishing relationship; 3) engaged: sufficient trust to enter services formally; 4) engagement for personal change: sufficient personal change to be actively and personally using the services to work toward personal goals

It is at Stages 3 and 4 that the HOPWA enhancements are critical, in helping clients maintain and strengthen the gains achieved in the first two stages and helping clients overcome some of the barriers (psychological, drug-related, medical) that stand in the way of personal goals. However, for the program, the reverse is true as well. The success (especially in terms of fulfilling quantitative objectives) of the more intensive program services rests on having a client base that is both large enough and sufficiently prepared for further engagement, to be able to take advantage of services and produce the desired program outputs.

Lesson 5: Outreach works.

The move to 24-hour services and infusion of new services as a result of the HOPWA enhancements led to an intensive review of all aspects of SafeSpace programming mid-1999. Outreach strategy was comprehensively reviewed and refined. It had been observed that although large numbers of outreach contacts were made, they were not necessarily among those most in need, and did not necessarily produce the desired engagement in new services. The increased numbers produced by 24-hour programming were overwhelming the Day Center.

Outreach strategy review and refinement continued througout 1999. The arrival of a second mobile unit in late 1998 allowed outreach to range relatively far afield into the outer boroughs. This is where many street youth had moved following the police clean-up of their old haunts in the Times Square area. Previously, outreach was allowed to operate in the early morning hours when some segments of street youth were most likely to be on the streets. This allowed outreach to locate and target the more difficult client sources. The second mobile unit also made it easier to form bonds with outreach clients. Clients could be offered a place to stay (at the newly-opened 24-hour emergency facility) and driven directly there by the second unit. These changes have produced a steady monthly intake rate and a level of interaction with SafeSpace staff builds trusting relationships. Such relationships are likely to produce intake and service engagement.

The more targeted approach is also reflected in the changing demographics of outreach contacts. Increasing proportions of the demographics are transgender or women.

Outreach services must also be carefully coordinated with core services to produce successful program outcomes. New more-difficult-to-reach clients are often reluctant to travel as far as Manhattan for services available at the central Day Center. This has impelled greater attention to bridge the gap between outreach and core services. The introductory phases of some services were extended onto the mobile unit. At the same time, greater attention was paid to getting outreach clients into the Day Center, and providing familiar faces once they were there.

The success of this more targeted, but still very low threshold model of engagement into housing and other services is illustrated by program data collected by outreach staff in a consistent format since mid-1999. The number of "new" (not previously seen) outreach contacts per month varies considerably, responding to changes in weather, staffing patterns, police activity and other influences outside the control of the program.

However, the number of return (previously seen at least once) outreach contacts per month varies relatively little and the ratio of number of outreach contacts to return contacts is low. This suggests that once a client can be coaxed into outreach services, many will return. They may use outreach services for relatively long periods of time before advancing to the next higher stage of service engagement, that of a formal intake into SafeSpace case management and other services.

The number of multi-service program intakes has varied relatively little. However, its variability is highly correlated with that of the number of return contacts. This suggests that a lengthy period of low-level contacts is necessary to produce entry to more intense services. It also means that programs relying on outreach to multi-problem populations may not see the fruit of that outreach for some time, and time to develop these routines and connections must be included.

SafeSpace Chronology

December 1997

- Staff plan to attend orientation meeting for MDI grantees at Columbia University.
- On the very day of the orientation meeting, staff receive news that long-term SafeSpace client and active peer educator Ali Forney had been shot and killed on the street in the early morning hours a day before. Most SafeSpace activities are cancelled. Instead the various groups organize funeral and memorial services at a nearby church for Ali.
- Discussions open with a large NYC substance-abuse treatment provider about contracting for services for SafeSpace clients. There are philosophical differences. Another provider is approached, but it lacks the experience with SafeSpace clientele.

February 1998

- SafeSpace executive director and program evaluation manager meet with ETAC evaluation technical assistance staff, who also pays an initial visit to SafeHome.
- There is an extended discussion of the role of HIV testing in SafeSpace's programs. While it is obviously a component of linking clients to HIV-related services, SafeSpace has a very cautious posture on testing. SafeSpace staff prefer that clients be stabilized and with a social and psychological support system in place before they consider HIV testing, as a number will be HIV$^+$. Premature introduction of HIV testing can drive fearful potential clients away, and homeless youth providers are haunted by the suicides of several youth tested a few years prior.
- While SafeSpace staff recognizes the potential benefits in taking advantage of ETAC's offer to train staff in interviewing and help set up computer systems, they also recognize this as a huge challenge. The multiple demands of the clientele leave little energy among the staff for record keeping or infrastructure development.

March 1998

- Discussions halt with the proposed substance abuse treatment contractor. Staff decides to add a substance abuse capacity to the Day Center instead.

April 1998

- Mediation and conflict resolution specialist starts work.

May 1998

- Substance abuse specialist is hired, a Certified Substance Abuse and Alcoholism Counselor.

June 1998

- First HIV+ client referred to Housing Specialist for assistance. Client referred to SafeHome for evaluation, but not eligible because of very serious drug and alcohol problems. Referred elsewhere for drug treatment.

August 1998

- Social worker and nurse practitioner jointly carry out first in-house HIV testing and counseling sessions.

September 1998

- An openly transsexual woman is hired as operations director. This opportunity to have a transgender role model available is unusual.

October 1998

- Day Center undergoes changes in preparation for new hours and programming. Physical remodeling of Center begins, as does planning for the expansion and new schedule.

November 1998

- The fully-equipped second mobile unit arrives.
- Day Center closed for major renovations. Street outreach is suspended. Staff participates in training in preparation for expanded services.

January 1999

- Yearly statistics are compiled. By end of 1998, MDI/HOPWA staff has served more than 400 clients.

March 1999

- Number of day-program intakes drops. Staff analysis suggests that paradoxically, this development is a result of the expansion of street outreach. With more services being offered on the mobile unit, and expansion to outlying neighborhoods which require a lengthy trip to SafeSpace's home base near Times Square, plus the time required to build trust in a new outreach location, relatively few outreach contacts are being induced to come into SafeSpace for intake and further services.
- Clients request formation of an Advisory Council to facilitate communication between staff and youths and provide youth with input on program improvements.

April 1999

- SafeSpace main building opens for 24 hours. Its 10-bed emergency dorm (mats unrolled on the floor of the conference room), makes it the second low-threshold 24-hour street youth facility in New York.
- Filling another gap in SafeSpace's continuum of care, SafeHaven opens. Funded by New York City, these scattered-site apartments will house youth in a pre-transitional program while they prepare for entrance into other programs.
- The new areas targeted by the mobile unit are supplemented by later hours to reach new subgroups, especially sex workers who are largely invisible before midnight.

May 1999

- Outreach department at full staff again. However, increasing client flow in building and programmatic demands of new 24-hour SafeSpace facility hours begin to overwhelm staff. Outreach recruitment drops off seriously as outreach staff are temporarily re-assigned to assist SafeSpace building staff.
- Outreach expands into yet more areas, including some previously untouched areas in Queens. In a milestone, NYC Parks Department gives permit to do outreach on the officially-closed West Side piers, a long-time hangout for gay youth.

June 1999

- HIV testing program is seeing few clients. In an effort to spur interest, the Institutional Outreach Worker is shifted part-time to the mobile unit, where he will offer education on and recruit for the HIV testing program. In one neighborhood, a linkage is formed with a local hospital for HIV testing of clients from the van.

- As part of institutional outreach, mobile unit participates in several street fairs, including Gay Pride events in four boroughs. These events get the word out to gay street youth, now dispersed out of their traditional haunts in the Times Square area by law enforcement crackdowns, that gay-friendly services are available, as well as publicize SafeSpace to gay youth who may later become homeless.

- SafeSpace closes its doors to clients for a week during this warm weather for staff training and review. Two months of 24-hour operations have shown the need for overhaul of policies and procedures. Several changes are made at the Day Center to make client flow more manageable: there will now be two mealtime sittings; the building will close a few hours a day to allow staff to catch up on record-keeping and planning, the number of daily intakes will be limited, and there will be a brief, formal orientation for new clients.

- New intake coordinator hired to standardize and speed up intake and referral procedures as well as facilitate improved intake record keeping.

July 1999

- First meeting of the Client Advisory Board. Created in response to the growing scale of the program, this monthly meeting will contribute to feedback from clients on program needs and successes.

- A new cycle of peer education begins with graduates of the previous cycle acting as mentors for new students. The mobile unit is a major incentive to participate in peer education, as graduates of the program can look forward to participating in outreach work themselves on the unit. This activity is important not only in learning about specific health information, but in strengthening peer educators' self-esteem and community connection.

August 1999

- Spurred by evaluation activities, staff starts planning new forms for use on the mobile unit. These will attempt to differentiate between first-visit and returning clients.

- At the Day Center, an experiment begins. The popular peer education course will have a third phase, to try to transition clients into the life skills program.

September 1999

- HIV testing on mobile unit begins, encounters first obstacle. Although educational and recruitment program has generated some interest, a bottleneck is created by the fact that the NYS Department of Health's required pre- and post-test counseling that accompanied phlebotomy takes around 45 minutes. The nurse certified to do counseling and phlebotomy is with the mobile unit only one day per week, so few clients can be tested.

- Other problems at outreach result from current staff vacancies. The current state of flux in both programming and scheduling make it difficult to recruit for these high-turnover but critical positions.

- Staff attempt to arrange for the NYS Department of Health's certification course so that they can administer the pre-test counseling in advance, reserve scarce nurse-phlebotomist time for phlebotomy and post-test counseling, as a way to overcome the logistical bottleneck.

- First clients recruited through mobile unit arrive at SafeSpace for services. Two are referred and escorted to inpatient drug detoxification wards, where they are admitted immediately.

October 1999

- With cooler weather, outreach focus shifts to indoor locations (bus, train, ferry terminals) where street youth are likely to go to get off streets. Planning for winter intensified, in anticipation that cold weather will drive more youth into the mobile unit, where they can be engaged and referred.

- Outreach worker must be replaced. Unstable schedules due to diversion to SafeSpace building make it difficult to regularize unit schedule and start recruitment. Recruitment is a challenge for these positions because of the irregular hours including after-midnight hours.

- Departure of program's nurse means no medical care available on mobile unit. Staff starts referring to local emergency rooms for crises.

- Staff still waiting for admission to NYS Department of Health HIV-counseling certification course. HIV testing on mobile unit still bottlenecked.

- To evaluate linkage between outreach and eventual formal intake into program, intake staff attempt to determine and record referral source for each new intake. Results are limited by the extreme reluctance of intake clients to give any information.

- For both security and evaluation tracking purposes, staff begin to investigate a photo-ID card system for admission to the Day Center.

November 1999

- Outreach staff spends much of this month on institutional outreach activity: developing new referrals for the rapidly approaching cold weather. New relationships are forged with 21 agencies.

- Staff also review pattern of outreach and referral now that mobile unit has had several months' experience in new locations, chiefly in the outer boroughs. Clients in these areas are interested in services, but reluctant to come all the way to the Day Center's mid-Manhattan area from their distant locations, and some may not have subway fare. Outreach staff start planning ways to bring more services out to these locations on the mobile unit, to meet this need.

December 1999

- Outreach staff vacancies make it difficult to assemble full teams to go out on all shifts. Much of this month, outreach staff work in Day Center, strengthening ties with clients they have gotten to know previously through outreach and assisting the Center staff, depleted with holiday-season vacations. Doll-making workshops led by one of the outreach staff prove to be an unexpected success.

- Intake coordinator leaves for another position. The substance abuse counselor assumes the vacant position, but now a new substance abuse counselor must be recruited.

January 2000

- Outreach staff vacancies are filled, teams start on full schedule again. Regular mapping trips reveal that youth are beginning to frequent traditional haunts in Times Square area again, now that the police sweeps have moved elsewhere. Two new areas in the outer boroughs are also discovered. Outreach will establish the hours at which these are active, and incorporate them into the mobile unit schedule.

- Of 14 referrals to the Day Center from the mobile unit, seven actually present themselves at the Center for intake, a somewhat higher proportion than in the recent past.

February 2000

- Staff started limited HIV testing on the mobile outreach unit. Still awaiting pre- and post-rest counselor training for outreach staff. Some clients have been expressing interest in pregnancy testing.

- Seven referrals to the SafeSpace Day Center, all seven present themselves.

- Outreach numbers drop off somewhat, as police sweeps disrupt some outreach locations and the van is out for repairs. Potential clients report they would like to enter the mobile unit, but are afraid because police often arrest clients as they exit the van. The unit ceases visits to one location because the youth frequenting it have dispersed after a pimp is killed there.

March 2000

- Outreach contacts rise again now that new outreach worker is hired and teams are complete. All nine referrals to the Day Center follow through. Two new sex-worker locations are found; mobile unit goes there.

- New substance abuse specialist starts work, institutes a new four-week substance abuse group at the Day Center, with Certificates of Completion to encourage participants to go through the whole cycle, and begins facilitating mandatory substance abuse groups at SafeHome. She starts introducing herself to and attempting to engage with the more difficult clients at the Day Center.

- Housing specialist attends training on NYC's entitlements programs for PWAs. Aftercare program formally started, including a structured 10-step transition program out of SafeHome. The specialist starts coordinating planning meetings for placing a pregnant SafeHome resident after discharge.

- SafeHome celebrates a milestone. Since its opening in 1995, 60 residents have been served. Of these, nine are currently in residence; two are known to have died; 24 are in SafeHome's recently started aftercare program; the whereabouts of the other 24 are unknown.

- In response to requests of outreach funding sources, staff attempts to ask outreach clients questions about their housing situation. As many are illegally doubled up, trading sex for a place to stay, staying in shelters or in the streets and subways, response is usually refusal or obviously false information, when it is not outright hostility. The need to collect data for administrative purposes frequently conflicts with the difficulty of persuading target populations to answer any questions.

April 2000

- Area in Day Center basement is renovated for new health clinic. This will provide complete primary medical care and referral on-site, staffed by the Mt. Sinai Medical Center's adolescent medicine program.

- Substance abuse specialist begins training, provides individual and group therapy services at both the SafeHome residential facility and the Day Center.

- Outreach contacts are down as schedules are disrupted with the departure of an outreach worker. Clients in some sex work locations become more difficult to reach as many acquire pimps in response to police sweeps and increased violence in these areas. Also, with warmer weather, youth find it easier to stay out all night. Six referrals are made to the Day Center and all follow through.

May 2000

- With recruiting completed, three complete outreach teams are able to provide more consistent outreach services. This is reflected in increased numbers of outreach contacts. Outreach staff locate two new sex work "strolls" and target them for outreach activity. Without a second mobile unit and the ability to scout and reach locations, outreach to these areas had been restricted.

- Numbers of shelter referrals begin to drop off, as the weather warms and staying out all night becomes easier.

- The outreach staff participates in institutional outreach at a Department of Health–sponsored health fair at the Rikers Island correctional complex, to get information out about services available after release, when many youthful inmates will have nowhere to go.

- Staff attempt to approve client tracking for both clinical and evaluation purposes. A senior outreach worker assumes a new set of administrative duties compiling and verifying the outreach service report system. Regular conferences of intake, outreach, and in-house evaluation staff are started, to ensure that clients are properly tracked and recorded as they move across service components.

- Expansion of HIV testing on mobile unit delayed because of need for certification course from NY state.

- Office space finally found for the substance abuse specialist at the main Day Center. Now that program members can find her more easily, she plans to move into a more casual and informal method of engaging clients and interesting them in substance abuse treatment.

June 2000

- To expand SafeSpace's visibility to sexual minority youth, outreach staff and mobile unit participate in

Gay Pride parades and other events in four boroughs. This institutional outreach should have long-term results in increasing recruitment in several months.

- Referrals from the mobile unit to the emergency facility at the Day Center continue. Both referrals actually follow through. They are housed and given intakes, showing the role of concrete services such as housing in engaging youth in needed services.

- Several groups are started or continued at the Day Center by outreach staff: sex education, men's group, and cultural sensitivity. These groups conducted by outreach staff are very popular, and having familiar faces leading them helps bridge the outreach to the day program.

- Substance abuse specialist continues to provide individual counseling sessions. These have stabilized to 30-45 sessions per month.

- The physician's assistant to staff the new medical clinic starts. Clinic starts running with limited services while arrangements are stabilized.

- Four graduates of the peer education program are now working as peer outreach workers on the mobile unit. The chance to graduate to outreach work proves to be a major incentive for enrollment in the peer education program that stresses HIV and related types of education. First baby is born to a SafeHome resident. While this is an occasion for joy, it creates new problems. The mother will not be eligible for SafeHome much longer, and the residence has no infant facilities. There are no facilities for HIV^+ adolescent mothers with infants anywhere. After exploring other options, the housing specialist accompanies the mother to the NYC Department of Homeless Services Emergency Assistance Unit to help her through the intake process and advocate for her. With some difficulty, the young woman achieves what is, unfortunately, the best available outcome for her: she is deemed eligible for shelter and is placed in an emergency shelter while awaiting placement in a Tier 2 (family) shelter. From there, as a homeless woman with an infant, it is possible that she will eventually be able to enter city-sponsored housing.

- A year after the restructuring of the SafeSpace programs, client flow has finally stabilized. Over the preceding nine months, repeat outreach contacts per month have averaged 115 (with additional 205 new contacts), producing eight emergency housing (overnight shelter) placements per month and seven intakes per month into the SafeSpace service system.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by SafeSpace, you are welcome to contact the project director and request technical assistance:

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