

Successful Strategies in Serving HIV-Infected Substance Users: A Case Study Report

INTRODUCTION

The epidemics of HIV and substance abuse, and more recently Hepatitis C, have had a major adverse impact on the health of low income and minority communities in the United States. Research shows that substance users are less likely to access HIV medical care than other persons living with HIV (Sherer et al., 2002; Palacio et al., 1999, Bakken et al., 2000) and that special care delivery strategies are needed to ensure that HIV-infected substance users gain access to the same treatment and medications that have reduced mortality and morbidity in other individuals living with HIV (NIDA, 1999a; Eldred and Cheever, 1998; Selwyn, 1996; Battjes, 1994; Battjes, Inciardi, 1994; Hartel, 1994; Stephens and Alemagno, 1994; Stone, 1999; Herman et al., 1997).

However, successful care delivery strategies for HIV-infected substance users challenge the best of service providers. Historically, the service systems for HIV medical care and substance abuse treatment have evolved separately, with different funding streams, eligibility criteria, licensure and regulatory requirements. Furthermore, the clinical cultures and approaches to care in the HIV medical care and substance abuse treatment system are quite different. Until recently there have been few efforts to establish strong linkages between HIV medical care and substance abuse treatment, as well as with the mental health and other support services needed to address the complex needs of HIV-infected substance users.

However, some organizations caring for HIV-infected substance users have implemented innovative methods and strategies to serve this population. As part of a grant funded by the Health Resources and Services Administration's (HRSA) Special Programs of National Significance (SPNS) Initiative, site visits were made to twelve programs across the United States during the summer of 2001 by researchers at the Health and Disability Working Group of the Boston University School of Public Health. The goal of the site visits was to document particularly innovative practices.

The twelve programs described below were selected from an original sample of 243 programs that responded to a survey about their program models, service delivery strategies, and approaches to serving HIV-infected substance users. In this report, we describe the methodology for selecting the twelve organizations for site visits, as well as some common themes across the innovative programs. This overall summary report is then followed by a set of twelve individual case studies that describe each program in greater depth.

METHODOLOGY

During the spring of 2000, a survey was mailed to 640 organizations. The organizations were selected to receive the mailing in one of two ways: they were either funded directly by HRSA through the Ryan White CARE Act, or they were identified by Ryan White CARE Act-funded programs or a group of key informant experts in the field of HIV and substance use

Of the initial 640 organizations surveyed, 243 or 38 percent, responded to the mail survey. From this group of 243, fifty programs were selected for in-depth telephone interviews. In selecting the fifty programs for telephone interviews, we drew upon information obtained through an extensive review of the literature on HIV and substance use, interviews with the expert key informants, and interviews with a group of consumers to identify essential features of successful, innovative programs.

The fifty survey respondents indicated program strengths in the following areas:

- Comprehensive and integrated service delivery for HIV-infected substance users;
- Strategies to support HIV medication adherence for substance users;
- Strategies to encourage and support substance abuse treatment readiness and engagement in treatment at different stages of readiness;
- Efforts to promote culturally competent services; and
- Other service innovations to lower the threshold to accessing care.

From the fifty telephone interviews, twelve programs were selected for site visits. The programs visited were selected, in part, for the strength of their program innovations. In addition, we sought a variety of program models in order to learn more about how services are implemented within different organizational structures such as substance abuse treatment programs, community-based primary care clinics, hospital-based programs, and public health clinics. Finally, we were looking for both geographic diversity and diversity of populations served. Although most of the programs described below are based in urban settings, several also serve rural areas. They include programs located in the northeast, mid-west, southern mid-west, northwest, west, and southern parts of the United States. They serve a broad population in terms of race, ethnicity and gender.

A team of two researchers conducted each site visit. Extensive notes were taken and transcribed into individual site visit reports. In addition, charts were assembled to conduct a cross-program comparison of services provided, staffing patterns, and client demographics. Both the charts and the draft site visit reports were sent back to the individual programs for review and corrections, and then revised by the study team.

RESULTS

The results of our site visits and analysis provided us with some common themes from the twelve innovative programs. Although the programs were based in very different organizational settings, they shared some common features. Most of the programs have implemented all or most of the following six innovative strategies:

- Efforts to integrate the delivery of HIV medical care, substance abuse treatment, mental health treatment, and support services either in one location or through a strong system of referral and linkage agreements;
- A multi-disciplinary team approach to care, including a broad range of professional and paraprofessional staff, such as physicians, nurses, substance abuse counselors, mental health professionals, case managers, and treatment advocates;
- Lowering the threshold to care, using a non-judgmental service delivery approach. This included “meeting people where they are at,” for medical care, for substance abuse treatment, and often for other services as well. It also included off-site outreach to high-risk individuals, either to follow up with and find people who drop out of care, or to bring HIV medical care and support services into homes or shelters;
- A commitment to providing state-of-the art HIV medical care to substance users, with strong efforts at treatment adherence;
- Strong efforts to provide culturally sensitive and competent substance abuse treatment and HIV medical care, including strategies such as hiring individuals who speak a variety of languages; hiring individuals from the community; and the involvement of peers as health educators, advocates and counselors; and
- Consumer involvement in program planning and implementation.

Although the programs had some commonalities, they also had some major differences. In addition to the differences in geographic location and provider organizational structure described above, the programs had different target populations, different staffing patterns, and different funding sources. Programs also varied in their interpretation of harm reduction, their adherence and retention strategies, and their level of consumer involvement in program design.

Below we provide a brief overview of each program (the individual case studies are described more fully in the case study reports). Following this introduction, we discuss how the common themes and features were actually implemented across programs.

Overview of Programs

Chicago Health Outreach (CHO) is a community-based health care organization that provides health, mental health, and support services to individuals who are homeless and have mental illness, as well as those who are refugees and immigrants. CHO began providing medical care for HIV-infected individuals in 1989. Today, CHO is part of a larger non-profit organization that also operates supported housing services through the Chicago Connections program. The two organizations work together closely. For example, Chicago Connections runs a 30-bed AIDS housing program on-site at the CHO

clinic. Approximately 10 percent of CHO's 11,000 clients have HIV; however, nearly all of these individuals have a recent history of substance abuse. More than half of their HIV clients are Black, a quarter are White, and 12 percent are Hispanic.

Continuum HIV Services is a non-profit HIV multi-service organization located in the Tenderloin district of San Francisco. The organization began as an adult day health center in 1989, but over time has evolved to provide a continuum of services for individuals who are homeless, injection drug users, and those recently released from jail or prison. Services provided include home and community-based health and social service programs for homeless individuals living in shelters or single room occupancy hotels, transitional case management and housing for the recently incarcerated, and a needle exchange program. Continuum HIV Services currently serves approximately 800 people living with HIV annually. About 80 percent of their HIV population are substance users, and about 60 percent have serious mental illness. About half of their clients are Black, a third are White, and the remainder are Hispanic, Asian or American Indian.

Family Services Woodfield (FSW) in Bridgeport, Connecticut, is a large multi-service organization with an extensive array of social services provided by 30 different departments, including an HIV/AIDS intensive case management/coordination unit and several mental health units. In contrast with the other agencies featured in this report, FSW does not provide any HIV medical care or substance abuse treatment services directly. Rather, FSW works closely with clients and community-based providers to coordinate services for HIV-infected substance users. The HIV/AIDS unit primarily serves the homeless and low-income HIV population of Fairfield County and, more recently, immigrants from Africa and Haiti. Almost half (47 percent) of those served are Black, while 30 percent are White and over 22 percent are Hispanic. Approximately 65 percent of the individuals they serve are active substance users or are in the early stages of recovery.

Health Care for the Homeless, Inc. (HCH) in Baltimore, Maryland, is a community health agency that serves homeless individuals by providing a variety of outreach, health care, mental health, and support services. HCH's main facility is located in the heart of downtown Baltimore, the area with the densest concentration of homeless persons in the city. HCH also has satellite sites in Montgomery and Frederick counties, and provides services in soup kitchens and shelters throughout the city of Baltimore, serving a total of 8000 individuals across the state. HCH opened its doors in 1985 and began providing HIV care in 1989. HCH serves approximately 276 HIV-infected homeless individuals each year. About 70 percent of these individuals are substance users. The majority of HCH clients are Black males (76 percent). Black females comprise 18 percent of the population. Their remaining clients are White males, with approximately the same proportion of men and women.

Health Services Center, Inc. (HSC--formerly AIDS Services Center) is a full-service, freestanding, non-profit clinic located in Anniston, Alabama. HSC has served people with HIV and AIDS since 1990 in Anniston (population 25,000), and operates seven satellite clinics across multiple rural counties. The main employers in the region are textile

factories and chicken farming, including large chicken processing plants. The total population of the service area is approximately 100,000. During the year prior to the site visit, HSC served 247 individuals living with HIV/AIDS. The population is almost equally split between Whites and Blacks, and 80-85 percent of HSC clients are substance users or have a history of substance abuse.

Heartland CARES is an HIV/AIDS multi-service organization in Paducah, Kentucky that provides a range of services including medical care, case management, counseling, and HIV outreach and education. Paducah is located on the Ohio River in western Kentucky, and is the sixth largest city in the state. The organization was three years old in 2001, when this assessment was conducted. Heartland CARES offers HIV-related nursing, mental health, and support services in collaboration with an on-site private infectious disease practice. Heartland CARES serves approximately 200 people living with HIV across a vast geographic area that includes Paducah, seventeen rural counties in western Kentucky, and fifteen counties in southern Illinois. Approximately half of Heartland CARES's clients are active substance users. Their clients are 75 percent white, 23 percent Black, and two percent Hispanic.

Mental Health Mental Retardation of Tarrant County (MHMRTC), in Fort Worth Texas, is one of 40 community mental health/mental retardation centers in the state. MHMRTC provides care to individuals with mental health diagnoses, mental retardation, autism, addictive disorders, and early childhood developmental delays. All individuals are served regardless of income. MHMRTC has four main divisions, one of which is the Addiction Division. Their HIV program is located in the Addiction Division, along with four substance abuse treatment programs. MHMRTCTC began serving individuals living with HIV/AIDS in 1995, and currently serve 140 people living with HIV each year. All of their HIV-infected clients have a current or recent history of substance abuse. Fifty percent of their clients are African-American, 44 percent are white, and 6 percent are Hispanic. One-third of their clients are women.

Multnomah County HIV Health Services Center (Multnomah) is an HIV medical care clinic operated by the county health department in Portland, Oregon. The Multnomah County health department serves a broad community of individuals living with HIV, only 25 percent of whom are substance abusers. However, as the state's only HIV medical care provider that accepts large numbers of uninsured individuals, the HIV clinic sees the vast majority of HIV-infected substance users in Oregon. The HIV clinic serves approximately 600 people per year from Multnomah and five surrounding counties. Seventy percent of their clients are white, and nearly 90 percent are male, which is representative of the HIV demographics in the area. The Hispanic population in Multnomah is growing rapidly, as are the number of HIV-infected Hispanic individuals. Approximately 12 percent of Multnomah's clients are Hispanic and 10 percent are African American, while the remainder are white.

The *Brooklyn Hospital Center PATH Program (BHC-PATH)* is a multidisciplinary HIV primary care and case management program with two hospital sites located at Brooklyn Hospital in New York City. Brooklyn is home to approximately 24 percent of New York

City's AIDS cases and the number of persons diagnosed with AIDS in the four zip codes surrounding the two hospital sites (3,769 as of March 2000) is larger than the total number of diagnosed AIDS cases in Oregon, Minnesota, or Kentucky. In 2000, BHC-PATH served over 700 people living with HIV/AIDS. Approximately 25-50 percent of these individuals were substance users. Over 70 percent of their clients are Black and 26 percent are Hispanic, with much smaller populations of white and Asian/Pacific Islander clients.

Project Bridge of the Miriam Hospital in Providence, Rhode Island, is an outreach and intensive case management program for HIV-infected ex-offenders. Rhode Island has mandatory HIV testing for all sentenced prisoners, and the infectious disease physicians from the Miriam Hospital provide all HIV medical care in state's prisons. Project Bridge works with clients post-release to ensure continuity of medical care with their physicians from Miriam Hospital and to provide necessary support services for ex-offenders returning to the community. Project Bridge served approximately 100 HIV-infected individuals during the four years prior to this site visit. The Project Bridge client population is 75 percent male and 25 percent female. Over half of their clients are Black, about a third are white and the remainder are Hispanic. All Project Bridge clients have substance abuse histories, and about three quarters have used injection drugs.

Special Health Resources of East Texas (SHRET) is a non-profit agency based in Longview, Texas. SHRET has three main divisions: a Substance Abuse Services Division; an HIV Division; and Wellspring, an 18-bed inpatient substance abuse treatment program for individuals living with HIV. SHRET provides HIV services to individuals residing in 43 primarily rural counties, while Wellspring is a statewide program. SHRET serves approximately 900 HIV-infected individuals each year. They estimate that between 25 percent and 50 percent are substance users. In 2000, 41 percent of SHRET's clients were Caucasian, 53 percent were African American, and 6 percent were Hispanic. Women represented 34 percent of the total population served.

The William F. Ryan Community Health Center (Ryan Center) in Manhattan, New York, is a Section 330 Community Health Center that has provided comprehensive primary and preventive health services to medically underserved residents for over 35 years. The Ryan Center is located at the crossroads of the Upper West Side and Harlem, and serves approximately 20,000 low-income persons annually. During 2000, the Ryan Center served 565 individuals living with HIV; approximately 50 percent of these individuals were substance users. Sixty percent of their clients are Hispanic, 30 percent are Black, and the remaining 10 percent are white, Asian/Pacific Islander, or American Indian. In addition to providing medical, mental health, and support services, the Ryan Center is the lead agency for the AirBridge Program, which coordinates health care and support services for people living with HIV who travel frequently between Puerto Rico and New York or Connecticut.

Common Themes

1. Service Integration

Numerous studies identify the importance of service integration in caring for individuals with multiple co-morbidities, including HIV, substance abuse disorders, psychiatric disorders, Hepatitis C, and other chronic health conditions or complex social needs. The core services necessary for an integrated system of care for HIV-infected substance users include HIV primary and specialty care, primary care for other health conditions, substance abuse treatment services, mental health services, case management, and support services. All of the innovative organizations have struggled to achieve service integration, primarily using three different methods: one-stop shopping; referrals, linkages and partnerships, and hands-on care coordination. Some strategies for achieving service integration using each of these methods are described below.

One-Stop Shopping

HSC in Anniston, Alabama, and **HCH** in Baltimore, Maryland, are two health care organizations that integrate care by providing a comprehensive scope of services on site, including substance abuse treatment. In 2000, after years of struggling with the severe lack of substance abuse treatment services in their rural area, **HSC** started their own outpatient substance abuse treatment program. The **HSC** substance abuse treatment program has three phases. Phase I is a ten week Intensive Outpatient Program (IOP), where clients attend treatment sessions three days/week for four hours each day. Phase II continues for an additional 10 weeks and includes aftercare and individualized care planning. Phase III is available as long as is necessary for each client, and provides continuing support on an individual basis. Although the IOP is based in the Anniston clinic, it is rotated through **HSC**'s satellite clinics, making it available to clients living in more rural communities. The addition of substance abuse treatment to **HSC**'s menu of services has made it easier for the medical and mental health staff to refer individuals for substance abuse treatment, and for clients to access this care when they are ready.

Although **HCH** has been providing HIV care since 1989, addiction services were not added to the service mix until 1995. A team of certified chemical dependency counselors, addiction counselors, and peer leaders provides **HCH**'s addiction services. **HCH**'s substance abuse treatment program embraces a continuum of treatment approaches from harm reduction to abstinence, depending on the client's readiness. As with **HSC**, there are three phases to **HCH**'s substance abuse program. Phase I includes a group that educates clients about addiction. The purpose of this group is to reduce harm but also to try to engage clients in treatment and introduce some structure to their lives. The group runs five days a week for two weeks. Individuals who complete Phase I can elect to proceed to Phase II. During Phase II, which includes six weeks of daily group sessions, participants begin to learn how addiction impacts their lives. Clients become involved with 12-step work, obtain a sponsor, work with an individual substance abuse counselor, and must successfully pass drug testing before graduating from Phase II. Phase III

focuses on relapse prevention and consists of two group meetings per week for four weeks, as well as individual counseling to learn about personal triggers that lead to relapse and behavioral strategies for avoiding relapse. **HCH** also hosts a weekly meeting of Narcotics Anonymous.

One of the substance abuse treatment programs also achieved a one-stop shopping service integration model by incorporating HIV primary care into its substance abuse treatment programs. Although each of **SHRET's** three separate divisions has a different focus, they collaborate internally to ensure that HIV medical care, mental health treatment, substance abuse treatment, and support services are provided to all HIV-infected clients receiving services from the agency. Located within the HIV Division are a physician, nurses, social workers, and licensed chemical dependency counselors, whose services are available to all **SHRET** clients at four different clinics in Longview, Texarkana, Paris, and Tyler. Wellspring, which is the only inpatient substance abuse treatment facility in Texas solely for individuals living with HIV, provides education about HIV treatment and addresses barriers to medical adherence.

Although not as broad, **MHMRTC** in Fort Worth has also achieved a one-stop shopping model. **MHMRTC** has a specialized HIV program that operates alongside adolescent residential services, dual diagnosis programs, a detoxification unit, and outpatient counseling. Three case managers each work closely with approximately 25 individuals to address their complex needs. **MHMRTC** uses a multi-disciplinary team approach to care both within the agency and with other agencies. Although the staff consists primarily of substance abuse treatment professionals, an HIV nurse specialist and physicians are also part of the treatment team. The HIV nurse specialist in the detoxification unit begins working with clients before they enter the detoxification program, when they are first scheduled for an admission date. She ensures continuity of care around medications, and if the client does not have a primary care provider, or is not adherent to HIV treatment, the nurse makes appointments and accompanies clients to appointments. The nurse also provides information about HIV, harm reduction, nutrition, and wellness, as well as information about medication adherence.

Referrals, Linkages and Partnerships

Two programs integrate services for HIV-infected substance users through partnerships with closely affiliated organizations. Although substance abuse treatment is not a core service of the **BHC-PATH** program at Brooklyn Hospital, **BHC-PATH** itself is located on the same hospital floor as an inpatient detoxification program. The two programs have developed a close collaboration. **BHC-PATH** peer educators go to the detoxification program weekly to talk with new clients about HIV, addiction, and their own experiences, and to encourage HIV testing and care. After this occurs, the **BHC-PATH** HIV counselor goes weekly to the detoxification program and asks if anyone wants to receive HIV testing and counseling. If an individual receives a positive HIV test, staff are able to ensure a prompt referral to HIV medical care because the two programs are closely linked, and the client is already familiar with some of the **BHC-PATH** program staff.

At **Chicago Health Outreach (CHO)**, HIV primary care services are provided at the CHO clinic through a multidisciplinary team of medical, mental health, and support service providers. The integration of substance abuse treatment with these other services has not been easy to accomplish. Residents of the affiliated housing programs could always receive their HIV primary care services at the **CHO** clinic, but clinic patients could not always access substance abuse treatment. This is largely due to the fact that Chicago only has five residential treatment slots for uninsured homeless individuals. Therefore, a strategy adopted by **CHO** to integrate care was to partner with the housing program and bring a certified addiction counselor from the housing program to the **CHO** clinic to provide counseling services. In addition, **CHO's** adherence counselors provide counseling and referrals to substance abuse treatment for active users at the housing programs. **CHO** is also working with other providers in Chicago to establish a continuum of substance abuse treatment that will range from outreach to detoxification to residential to ongoing outpatient treatment, for individuals without insurance.

Other agencies also use linkage and referrals to integrate care. San Francisco has a comparatively accessible substance abuse treatment system for people with HIV. There is no discrimination against people with HIV in residential treatment, and the Title I program funds slots for people with HIV. Therefore, **Continuum** conducts a substance abuse assessment of new clients in all of its programs, and staff work with clients on harm reduction, overdose prevention, mental health issues, and abscess prevention. If a client is ready for treatment, **Continuum** has strong collaborative relationships with local substance abuse treatment providers, primarily residential programs and outpatient counseling, to which they can refer clients.

The **Ryan Center** is not licensed as a substance abuse treatment program, therefore formal substance abuse treatment services are provided through referrals. The **Ryan Center** has formal linkage agreements with agencies that provide detoxification, residential substance abuse treatment, methadone maintenance, and housing support services. Because it can be so difficult to engage clients in substance abuse treatment, if clients are at the **Ryan Center** and agree to enter treatment, **Ryan Center** staff will arrange for the substance abuse program to come and pick the client up right then. In addition to outside linkage agreements, three programs at the Ryan Center have certified addiction counselors on staff: the harm reduction program, the homeless program, and the community support dual diagnosis program. Therefore, substance abuse counseling is available as part of an individual's treatment plan through these programs.

Hands-On Care Coordination

Some programs integrate services through a strong care coordination model. For example, **FSW** includes an HIV/AIDS intensive case management/coordination unit, consisting of nurses, social workers and a substance abuse advocate who plays a major role within the unit. The substance abuse advocate is responsible for assessing client readiness for substance abuse treatment; and for referring and often accompanying clients to primary care medical, detoxification services, counseling and treatment. The advocate

charts and monitors each client's adherence to HIV treatment. The advocate is also responsible for building and maintaining connections with substance abuse service providers and maintaining a close connection with each client's case manager. In addition all HIV-infected clients receive intensive case management at **FSW**, with some of **FSW's** case managers out-stationed at the major HIV clinics in the area. The case management staff works closely with a home health nurse who specializes in HIV treatment adherence. **FSW** has made it a point not to duplicate other services available in the community, but rather to create a model of care that promotes communication and linkage across services for HIV-infected substance users.

Project Bridge in Providence, Rhode Island, offers yet another care coordination model of service integration. **Project Bridge** provides intensive case management and medical and social support to individuals after their release from prison. Like **FSW**, **Project Bridge** does not provide medical services or substance abuse treatment directly. However, M.S.W. social workers who serve as case managers accompany clients to all medical appointments; while paraprofessional outreach workers accompany clients to all non-medical appointments, such as appointments to apply for housing or social security benefits. This intensive level of case management and care coordination ensures that clients make and keep their appointments, and are able to keep in touch with a member of the **Project Bridge** team about the implications of their medical and non-medical visits, as well as to discuss next steps.

2. Multidisciplinary Team Approach to Care

All twelve of the case study sites used a multidisciplinary team approach to care. The team usually included nurses, mental health professionals (often social workers), and case managers. Some of the teams also included physicians, nurse practitioners, physician assistants, nutritionists, substance abuse counselors, psychologists, psychiatrists, and pharmacists. Finally, many of the teams include paraprofessional or non-professional staff such as outreach workers, peer educators, adherence specialists and treatment advocates.

However, even when service providers employ a diverse, multidisciplinary clinical staff, this does not ensure that staff will communicate effectively with one another about individual clients. The innovative programs provided many examples of effective multidisciplinary team communication to improve the coordination and delivery of services to individual patients or clients. The main vehicle for multidisciplinary team communication was case conferencing.

One form of case conferencing involves regular meetings (usually weekly or every other week) of the entire multidisciplinary team to discuss cases in depth. By studying an individual case as described and approached by different disciplines, staff can learn about the complexities of the case and apply this knowledge to their other clients. This model of case conferencing, besides being helpful in thinking about an individual client, represents

a teaching model where the various disciplines learn from the each other through discussion and brainstorming.

The **BHC-PATH** Program exemplifies this system of case conferencing. The **BHC-PATH** program's team members meet as a group three times per month; once for a patient flow meeting, once for a journal club, and once for a case management meeting. In the case management meetings, the staff discusses the cases that present the greatest challenges for each service provider.

Another form of case conferencing entails reviewing each individual scheduled to be seen for an appointment on a given day or week. Several programs utilized this model. At **Heartland CARES** the entire multidisciplinary team meets weekly to review all clients who have clinic appointments scheduled for the following week, and together with the physicians, the team develops a visit plan for each client. The visit plan includes a list of all staff the client needs to see during the visit. This information is recorded on a board, and as the client concludes his or her session with each provider, the provider makes a check on the board to indicate that the session is completed.

Project Bridge case managers attend a weekly meeting with the infectious disease physicians, nurses and other medical staff at the Miriam Hospital that focuses on individual patients, as well as a weekly internal team meeting for case conferencing. In addition, **Project Bridge** convenes quarterly case conferences for each client. The key individuals from all involved agencies who provide services to a particular client attend these meetings, where they exchange information regarding the client's treatment, progress, and goals. Clients also attend the case conferences and provide input.

A few of the programs have daily meetings about the patients who are due in clinic that day. For example, the **Multnomah** clinic staff meets at the beginning of each day to talk briefly about all clients who are scheduled for clinic that day. The **HSC** staff use their one or two hours drives to their satellite sites creatively as a regular time for case conferences about individual patients.

3. Lowering the Threshold to Care

A key component of all of the innovative programs was efforts to lower the threshold to care. All of the case study programs were very aware of the many barriers to care for HIV-infected substance users and took steps to address these barriers. To lower the threshold to care, some programs took their services, including medical care and substance abuse treatment, into home and community-based settings. Most of the programs conducted outreach, either to engage new patients in care or to re-engage people who are lost to follow up. Finally, all of the programs used a harm reduction approach in working with HIV-infected substance users to encourage retention in care.

Taking Services to Clients

HCH and **CHO** clinical staff provide “home visits” for their homeless clients, usually in homeless shelters. At **CHO**, although primary care services are provided in the shelters, most other HIV medical services need to be provided at the clinic. Therefore, clinicians need to develop relationships with clients that will encourage them to come into the clinic for their HIV care. When the primary care team goes to the shelters they often bring a mental health case manager or housing case manager with them in order to help establish these relationships.

Continuum in San Francisco has a mobile clinical team. **Continuum’s** nurses and case managers go to the single room occupancy (SRO) hotels and shelters to provide nursing and social support services, but the program does not employ physicians. **Continuum** realized they were limited in what they could do in the SROs and shelters because none of their staff could write prescriptions. In addition, none of the clients were receiving primary care, psychiatric services or antibiotic medication. Thus, **Continuum** initiated the Tenderloin Cares project, a collaboration with four other agencies, each of which contributes different clinical resources. Now the mobile clinical team includes two part-time psychiatrists, a neuropsychologist, a community health worker, two nurse practitioners, and a physician. Although these staff are funded by different agencies, they function as a team when they go to the SRO hotels.

BHC-PATH’s multidisciplinary team moves itself rather than moving patients. The entire team moves between their two hospital campuses for clinic sessions, rather than expecting clients who get care at one campus to go to the other for different services. While the majority of the team conduct a clinic at one campus, a social worker, case manager, and receptionist remain at the other campus to maintain a presence and address any problems that arise between clinic sessions. This makes it easier for clients to access care, particularly for people who are unlikely to travel out of their neighborhoods.

While many densely populated and ethnically diverse areas, such as Brooklyn, Baltimore, and Chicago, benefit from the mobility of clinicians, this medical mobility is especially vital for rural areas. **HSC**, **Heartland CARES** and **SHRET** serve large, primarily rural regions. In addition to their primary clinics, each operates satellite clinics in more distant rural areas where they provide an array of medical, mental health, and support services. In addition, each program offers outpatient substance abuse treatment at its rural satellite offices. Of necessity, some of the satellite programs are structured differently from the programs at the central clinic. For example, certain services may be offered less frequently. However, given the transportation issues for clients and the lack of providers in rural areas, these mobile programs make care more accessible to HIV-infected substance users living in rural areas.

Conducting Outreach and Follow-up

All of the innovative programs employ staff that conduct outreach, either to bring people in for care or to find people who have missed appointments. At **Multnomah**, a home visiting nurse goes into the community to find people who are lost to follow up. The **Ryan Center** has a mobile medical van that goes into communities where there are large numbers of adolescents and injection drug users. Many of the programs employ outreach workers who use a broad range of strategies. Below, we describe two additional examples of the different outreach and retention strategies.

MHMRTC has three outreach teams that go to street corners, bars, underpasses, shooting galleries, shelters, apartment complexes and jails. They provide bleach kits, condoms, HIV and substance abuse education, and harm reduction information. All outreach workers are trained in HIV counseling and testing. The outreach workers host alternative parties where they rent a hotel room to distribute HIV and substance abuse information and to give people an opportunity to take showers. They also organize cookouts in housing projects to attract children and their mothers with free hot dogs, balloons and games. This strategy has been particularly effective in reaching out to women.

MHMRTC also has a formal system for following up with HIV-infected individuals who are discharged from the detoxification unit. The HIV case manager (a certified addiction counselor) and the nurse stay in contact with people for six months. After the first three months out of detoxification, they conduct a formal follow-up visit, and then continue to follow the client for an additional three months. The goal is to ensure that the client stays connected, is following up with referrals, and is reducing risky behaviors.

In the Tenderloin district of San Francisco, homeless individuals must wait in long lines to get food, shelter beds, benefits, and cash assistance. Many of these individuals have serious mental illnesses and addiction, and have concerns about basic subsistence needs. HIV medical care is not their primary focus. **Continuum** tries to deal with this by sending their social workers, nurses, and peer counselors into the neighborhood with food packets. They also visit people in the parks and single room occupancy hotels, teach people about vein care, look at their abscesses, and try to build the trust to bring people into clinic-based HIV medical care.

Harm Reduction

Harm reduction approaches to engagement, retention, care and treatment were a cornerstone of the service models at all twelve of the innovative programs. Several of the programs model their interventions on the Stages of Change theory, and some also use motivational interviewing techniques. A variety of different methods and approaches to practicing harm reduction, as well as different interpretations of the term itself, were found in the programs. Staff from multiple programs recounted the difficult journey of their organization in moving from an abstinence-only model of care to a model that also embraced harm reduction.

For all of the programs, harm reduction is interpreted as an approach to care that treats each client as an individual, and with respect. In return, for most programs, harm reduction also implies certain expectations of clients. Often, using harm reduction, staff assist clients to identify their own goals, which then become the focus of treatment. Staff then works with clients to move one step at a time toward meeting their stated goals and practicing safer behaviors.

At **CHO**, for example, most people come to the clinic needing care for an injury or an illness, not for HIV care or substance abuse treatment. Staff focuses on building relationships and addressing the basic needs for food, shelter, clothing and treatment for the acute medical problems that are articulated by clients. Then, as those needs are met, a relationship begins to be built with those clients. Once the relationship is strong enough, the staff begin to address the HIV and substance abuse issues.

Continuum also tailors their interactions to individual circumstances. In keeping with their harm reduction approach, they try to meet client needs but they also place expectations on clients. For example, **Continuum** staff work with clients to understand that acceptable behavior for someone on parole is different from acceptable behavior for someone who is not on parole. Or, acceptable behaviors in an SRO hotel are different from what is acceptable in a community environment such as an adult day health center or a community meeting. Consistent with the harm reduction approach, **Continuum** does not bar people from services if they are using drugs. The one exception to this is their adult day health program (except for methadone treatment or medical marijuana) because of the group setting. Rather than focusing on drug use, **Continuum** focuses on promoting acceptable behavior, particularly if people come into the setting high and engage in behavior that is disruptive to the group.

Some programs provided specific examples of how harm reduction worked for individual clients. At **MHMRTC**, an HIV-infected homeless mother began treatment a year earlier. Upon beginning treatment, her immediate goal was to obtain food and shelter for her children and herself. She and her children were placed in a residential program. She participated in a “life skills group” where she learned strategies for completing tasks and coping with overwhelming situations. Her case manager taught her about area resources, and helped her to make medical and other appointments. The woman dramatically decreased her drug use as she felt more empowered. Her self-esteem improved, and she became better equipped to cope with life challenges. As her medical, psychological, and social situation stabilized, her goals changed. Rather than a focus only on immediate goals, she set her sights on obtaining housing in a particular housing development that she had always admired but thought was beyond her reach. Her case manager informed her that she could have an apartment in the development but she would be required to remain drug free. By that time, the woman had been successful in several other areas of life, and believed that having the home she longed for was actually within her power. She chose and was able to abstain from drug use and is currently living in the housing development with her children.

Heartland CARES provided two more examples of how harm reduction worked with their clients. One uninsured client was consuming one quart of vodka each day. Over

time, working with his physician, substance abuse counselor, and other members of the **Heartland CARES** team, he reduced his consumption to one-half pint per day. As his physician described it, they worked on reducing the vodka intake one sip at a time, as there were no detoxification facilities available in the area for the uninsured. This man is now able to keep a job, has reduced the damage to his liver, and no longer passes out and misses his HIV medications. A second **Heartland CARES** client was living on the streets and using drugs. Using a harm reduction approach, staff worked with him to move into a shelter and begin methadone maintenance treatment. He now gets warm meals each day in the shelter instead of eating from a garbage can. He is also using condoms when sexually active.

Many of the programs use a harm reduction approach in all aspects of care, not limiting the application to substance abuse alone. **Continuum** in San Francisco describes their broader use of harm reduction as follows:

- The nurse at the needle exchange program teaches people about vein care and checks for abscesses in order to reduce harm for drug injectors.
- The physicians and nurse practitioners use medication contracts with some clients to manage pain medications and address drug interactions.
- Staff work with clients who are in abusive relationships to make back-up plans and identify safe spaces if they are in danger, reducing potential harm for clients experiencing domestic violence.
- Mental health staff develop no-harm contracts with individuals who are feeling suicidal.

Some of the programs have always promoted a harm reduction approach to care, while others began as abstinence-based models and have struggled to introduce this approach more recently. The **Ryan Center** in New York has had a formal harm reduction program since the early 1990's. Although they have designated staff in this program, including a substance abuse counselor, a harm reduction health educator, and three peer educators, all staff at the **Ryan Center** are required by the city to be trained in harm reduction techniques. This was a major challenge for some of the peer educators, who are individuals in recovery, and believe strongly in the abstinence approach. They spoke of how difficult it has been for them to move toward and accept the harm reduction approach to substance use.

MHMRTC also has a relatively long history of using harm reduction approaches, however, they experienced a remarkable evolution from an abstinence-based model to a harm reduction model. **MHMRTC** developed from a strict abstinence model, tracing its roots to a goat farm where alcoholics were sent to “work-off” their “obsession” for alcohol. However, in the early 1990's, **MHMRTC** began exploring different methods for working with HIV-infected substance users and began to adopt a harm reduction approach to engage them in HIV treatment. They discovered that the harm reduction approach was producing much better client retention rates and reducing staff burnout. At that point, the agency leadership made a decision to adopt the harm reduction approach to outpatient substance abuse services, although retaining abstinence as the ultimate goal.

Although **Continuum** has employed harm reduction strategies for over ten years, they described much struggle and debate over harm reduction among the staff, particularly among those individuals who were in recovery themselves, similar to the **Ryan Center**. At first the idea of harm reduction was extremely threatening to staff in recovery, who credited recovery with saving their lives. These individuals strongly believe that recovery is the best way to help others. To address this, **Continuum** has constant discussions and training for staff about harm reduction, ultimately learning that harm reduction addresses the needs of staff as well as the needs of clients. For staff, it is painful to work with clients who constantly fail. Using the harm reduction approach, clients can take more steps forward, and every step forward with a client serves as encouragement for staff as well. **CHO** had a very similar experience, finding that harm reduction was very difficult for some staff to embrace, especially the administrative staff and the peer staff working at the housing programs. Now, all housing program staff, many of whom are in recovery, receive mandatory four-day harm reduction training. The staff need and receive a great deal of individual supervision, mentoring, and the opportunity to vent their feelings about how harm reduction can feel like enabling clients. Recently, **CHO** realized that the administrative staff also needed training, because when a client comes in to the clinic high and begins to act out, the first people they encounter are the front desk staff. However, these staff are the least likely to have been trained in harm reduction. They are now being trained in harm reduction principles as well.

Multnomah offers one final example of the struggle to implement a harm reduction approach to care. Although harm reduction is consistent with the public health approach to care, public health providers do not automatically adopt harm reduction. Several **Multnomah** clinic staff were strong advocates of abstinence, and some are in recovery themselves. For these individuals, introducing a harm reduction philosophy into the clinic was a major change in organizational culture. This has been dealt with by spending a great deal of time talking and problem solving about how to deal with difficult situations. Staff were given training in harm reduction, as well as on drug interactions, overdose prevention, methadone maintenance, and using behavioral contracts.

4. Treatment Adherence

Support for adherence to medical treatment is a core element of all the programs. The innovative programs were unanimous in stating that their policy is to explain and offer anti-retroviral therapy to all patients who are clinically eligible for therapy, regardless of their use/abuse of alcohol or drugs. At the same time, many of the programs acknowledge that adherence is not always easy for clients who have mental illness, are homeless, or are actively using drugs. All the programs have clients who continue to use drugs and are adherent to treatment, but many substance-using clients have difficulty with adherence. As a physician from the **BHC-PATH** program noted, “Research shows that physicians are not very good at predicting which of their patients will adhere to treatment.”

Therefore, rather than making judgments about potential adherence before it is tried, the programs offer special support services to improve and encourage treatment adherence. Some of the more common adherence strategies include:

- Multiple sessions with the primary care provider, pharmacist, or other professional staff to discuss treatment options, logistical issues, lifestyle concerns and potential side effects;
- Counseling to address mental health and substance abuse issues;
- Intensive individual support and education about side effects, nutrition, and life skills that support decision-making and adherence;
- The use of adherence reminders, such as pill boxes, beepers, alarm clocks, and calendars; and
- Distributing medications on a weekly basis in order to see clients more frequently and review any problems with the medications.

For the innovative programs, the concept of treatment adherence is not restricted to taking medications. It also pertains to keeping medical appointments. Several programs mentioned that the use of charts and graphs that plot an individual's CD4 count and viral load over time are useful tools. Clients look forward to their appointments, where they can review their progress and feel a sense of achievement when results improve.

In addition to the services and strategies described above, many of the programs have their own unique strategies for addressing adherence. At **BHC-PATH**, providers will often work with clients to test new adherence strategies, using M&Ms rather than medications, to see what is feasible. At **CHO**, adherence counselors offer a \$5 weekly incentive to clients to come in and refill their pillboxes for the next week. **Heartland CARES'** adherence program is a "mentoring program" that serves the dual functions of supporting adherence for people with complicated life circumstances, and encouraging these people to then serve as mentors to others to support their adherence. At **Heartland CARES**, the adherence counselor works with the mentors to develop and support the life skills necessary for adherence, and a nurse runs mentoring groups that teach people about HIV self-protection and self-care. Once individuals have completed the program, they can serve as mentors to other clients.

At **Multnomah**, the pharmacist is involved in the initial discussion about HIV treatment with clients and primary care providers. The pharmacist uses motivational interviewing with clients to address adherence. She talks with clients about the appropriate time to initiate medications, strategies and tools for taking medications correctly, and options for addressing barriers to medication adherence. Some clients say that they prefer discussing their adherence difficulties with the pharmacist because they "don't want to let their doctor or nurse down."

Finally, the **Ryan Center** has two adherence programs. The first program is run by a nurse in the primary care clinic, and is offered to all clients on anti-retroviral therapy. The program includes weekly adherence groups for clients, as well as case conferencing by staff about challenging patients. The second program at the **Ryan Center** is a specialized treatment adherence program that provides intensive and aggressive outreach and follow-

up for 75 clients who are at risk of falling out of care or who are lost to care. Almost all of the clients in this program are active substance users. This program is designed to give clients the extra attention and support that they need to adhere to their medications and to address their substance use. Two HIV care technicians and a case manager conduct community outreach to find patients and re-engage them in care. The adherence nurse organizes relapse prevention groups, health education groups, acupuncture, and education counseling groups. This program uses tools and incentives such as watches with beepers, pillboxes, nutritional snacks, and subway or bus cards as incentives. In addition, the program makes use of pocket health journals that are given to clients to document taking their medications and to monitor their CD-4 counts, lab results, and appointments. The journals are small and fit conveniently into a back pocket or pocketbook.

5. Cultural Sensitivity and Cultural Competency

Another feature common to all the programs is their understanding of the importance of being sensitive and flexible around the culture of their consumers. The innovative programs seek the counsel of the people they serve and try to provide services that increase accessibility and, ultimately, improve adherence. Ethnicity, race, language, and sexual orientation are the first ideas that come to mind when thinking about cultural issues. However, for programs serving HIV-infected substance users, there are other important cultural concerns, such as the culture of homelessness and poverty, prison culture, and the injection drug user culture, that come in to play. Many of the programs were very open about their struggle to overcome their own gaps in awareness and knowledge of different cultures, as well as cultural tensions among their different client populations. The most common strategies for ensuring cultural competence and sensitivity include hiring practices, staff training, and using peers and indigenous persons from the community. Perhaps the service areas with the most cultural diversity among the twelve innovative programs are CHO and BHC-PATH.

CHO serves homeless individuals and families who speak over 24 different languages. To help support the enormous diversity of their consumers, the organization includes a Multicultural Services Division. This division has 110 interpreters who speak 28 different languages, and have translation capacity in 20 languages. Furthermore, the division also develops materials and provides training on language rights and cultural competency for many other organizations in Chicago.

CHO conducts orientations and quarterly seminars for all staff on a host of cultural competency topics. The organization views cultural competence as an ongoing process: “you can be here ten years and still have lots to learn.” In addition, staff struggle with a certain amount of tension between the different populations they serve. Homelessness has its own culture and is accompanied by a significant amount of stigma. The program has found that immigrants and refugees, who are often quite frightened of the prospect of becoming homeless themselves, are frequently uncomfortable being around homeless individuals. This presents a number of challenges for the staff as they attempt to work as sensitively as possible with these complex social differences.

BHC-PATH serves a diverse and constantly changing community. The program has addressed many cultural issues through their hiring practices, staff training, and work with other community-based organizations. Two-thirds of their staff are Latino, Caribbean, African American, or Asian. In addition, **BHC-PATH** works with local community-based organizations from the Haitian, African, and Latino communities to bring culturally relevant case management services into the clinic. Still, there remain cultural differences between staff and clients who share a common ethnicity, but a different life experience. As one foreign-born clinician stated it, her “American experience” has led her to have a different view of the HIV virus than many others from her country of origin. She still struggles with the religious and cultural views of her HIV/AIDS patients, but has found that acknowledging and respecting their religious views puts her in a better position to suggest that “God probably would not object if they took medications.”

Many of the organizations are working to address the changing demographics of the HIV epidemic in their service areas. Although Oregon is a less diverse state, the **Multnomah** clinic has a growing number of Hispanic and African American patients. Staff work with community-based organizations in the minority communities to address cultural issues and provide referral services. Like many of the other innovative programs, **Multnomah** provides ongoing staff training in cultural competence. The clinic also has Spanish speakers in all staff capacities, including physicians, nurses, social workers, and receptionists.

SHRET has seen a considerable increase in the Latino population in their area of Texas. To be able to effectively work with the population, they hired a physician from Mexico to work in the clinic and are hiring bilingual case managers. However, it has been difficult to find bilingual case managers, nurses, and other staff. Thus far, most of their clients have been bilingual, but an increasing number of clients who speak only Spanish are anticipated.

Cultural competence at **Continuum** also includes knowledge of, and the ability to relate to, the drug culture. In the drug culture, interactions take place through barter: “you have a drug, I have housing, let’s make a deal,” or “I can not give you this but I can give you that.” Continuum staff needs to be comfortable with this kind of exchange in order to work with their clients who are active drug users, and move them toward HIV care and treatment.

Two organizations have been able to supplement their financial resources as a direct result of their effort to be more culturally competent for their consumers. Both **CHO** and **FSW** raise revenue by offering interpreter and cultural competence training to the larger community. **FSW** has a significant deaf outreach service program that offers sign language assistance.

A few organizations increased cultural competency within the different organizations by hiring peers as part of the program staff. The peers often function as outreach workers,

client advocates, HIV educators, or case managers. In some cases the peer staff are former substance abusers, some are HIV-infected, while others are individuals who grew up or live in the community. For example, **Project Bridge** has hired paraprofessional outreach workers who grew up in the area of Providence where many of their clients also grew up. The **Ryan Center** HIV care technicians are individuals who are also former substance users in recovery. They also hire peers to work in the AirBridge and harm reduction programs. The **BHC-PATH** program has a staff that is totally reflective of the demographics of the client population they serve. Finally, **CHO** hires peers and consumers to work in all of its programs.

6. Consumer Involvement

The final strategy common to the innovative programs is a strategy of true consumer involvement. Some of the programs have developed strategies to involve consumers in program governance, advocacy activities, or on advisory boards. Below are several examples of these efforts.

Multnomah's Consumer Advisory Board (CAB) was established two years ago. Approximately eleven consumers and two staff members attend regular meetings. The CAB has hosted an Open House on World AIDS Day; developed a client newsletter; provided input on grant applications; participated in external meetings such as the Planning Council, the community health council, and Ryan White CARE Act meetings; and participated in hiring interviews for new staff at the clinic. In addition, the CAB co-chairperson attend the **Multnomah** clinic's all-staff meetings. Through its work with the Planning Council, the **Multnomah** CAB has had an impact on how the transportation system works in the area. Another goal for the CAB is to recruit new members, particularly members of color.

Multnomah has also developed other methods for obtaining consumer input. These include putting a suggestion box in the lobby, which is used quite often. They have also placed a computer with Internet access in the waiting room for clients to use. Finally, the **Multnomah** clinic is in the process of recruiting four consumers to serve as part of the clinic's quality improvement team. Through the CAB and these other activities, consumers are beginning to play a more active role and have a bigger impact on service delivery.

CHO hires consumers in all of its programs. In addition, the organizations board is composed of a majority of consumers, including some who are living with HIV. Each of **CHO's** programs also has a CAB. **CHO** encourages consumers to be part of the Care Coalition in Chicago and to help with advocacy work. For example, in the mental health program, consumers participated in a breakfast for legislators. The CAB has also participated in program development, and has organized dances and social events.

At **HCH**, consumer involvement is focused on participation in advocacy events. Each year, staff, clients, and Board members convene at a statewide advocacy day in

Annapolis to discuss needs and barriers to care with legislators. **HCH** administrators note that legislators appear to be deeply impacted by the consumers' presence and comments.

The **Ryan Center** involves consumers in a range of ways. In addition to the peers working in several of the programs described above, the **Ryan Center** has a Community Advisory Group that acts as their agency Board. The Community Advisory Group meets on a quarterly basis and advises the Center on all aspects of its HIV program. A core group of six consumers is very involved in the advisory group. They also participate in the development of grant proposals, offering ideas and input for funding.

SUMMARY

Each of the twelve innovative programs found different strategies to effectively serve HIV-infected substance users. These programs demonstrate that HIV-infected substance users can be effectively served by highly diverse organizations working under very different organizational, financial, and geographic constraints. However, the effort to serve this population well takes strong organizational leadership and vision. Each of the programs demonstrated the ability to “think outside the box” and the willingness to test new strategies. In addition, the staff demonstrated profound respect for, and understanding of, the complex needs of their clients, and deep compassion and commitment to meeting these needs.

Themes that occurred consistently across the programs were the importance of finding ways to achieve service integration, developing a multi-disciplinary team approach to care, lowering the threshold to care, providing intensive outreach and follow-up services and state-of-the art HIV medical care, offering culturally sensitive and culturally competent services and engaging peers and consumers as partners in care. By using most, or all of these strategies, each of these programs has had success in serving the HIV-infected substance-using population.

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