Promoting engagement and retention in HIV medical care among hard-to-reach populations
Produced by:

Serena Rajabiun, Casey Rebholz & Carol Tobias,
CORE/HDWG (Center for Outreach Research and Evaluation, Health & Disability Working Group) Boston University School of Public Health

Alison Frye, Cascade AIDS Project
Leah Holmes, Project Bridge
Nancy Blaney, Caring Connections
Monique Green Jones, Horizons Project, Wayne State University
Debra Dekker, Whitman-Walker Clinic
Allison Jones and Judy Bradford, Fenway Community Health Center
Cynthia Davis, Drew University Mobile Health Outreach Project
Aaliyah Messiah and Maria Lindsey, Konnect II Program, POCAAN
Marcia Anderson, Well-Being Institute
Melinda Tinsley and Robyn Schulhof, HRSA

Kim Bieler, design & production

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In the last decade, advances in HIV treatment have improved the health and quality of life for people living with HIV and AIDS (PLWHA). The Ryan White CARE Act provides funding for programs and services to ensure that PLWHA have access to HIV medical care and treatment. However, several challenges continue to prevent many people living with HIV and AIDS, especially in poor and minority communities, from reaping the benefits of medical advances in appropriate HIV medical care and treatment.

To learn more about these challenges and approaches to overcome them, the HIV/AIDS Bureau of the Health Resources & Services Administration (HRSA) through its Special Projects of National Significance (SPNS) funded the Outreach Initiative, ten innovative programs designed to implement and evaluate strategies to engage and retain underserved, hard-to-reach HIV-positive persons in medical care. The goals of the Outreach Initiative were to find people newly diagnosed with HIV and bring them into medical care, find and reconnect people who dropped out of HIV medical care, and retain people known to be at risk for dropping out of care. The ten programs were located in urban areas and implemented by community-based organizations working in partnership with hospitals, university medical centers, or a county health department (seven programs), community-based clinics (two programs), and one hospital-based clinic.

The programs reached out to diverse populations considered to be underserved and at risk for not receiving HIV primary care, including:

- Persons of color, primarily African-Americans and Latinos
- Youth
- Women
- Men who have sex with men (MSM) of color
- Active substance users
- The homeless
- Sex workers
- Recently incarcerated individuals
- People with a history of mental illness

The programs used a variety of interventions to engage and retain these hard-to-reach populations in HIV care. Two programs conducted scripted behavioral interventions with known sporadic users of medical care to improve their retention in care. Several programs provided outreach, case management, and other ancillary services, and gave assistance with navigating the health systems in their area. Another two programs provided training in health literacy and life-skills building, and one program provided outreach and medical services to PLWHA at their residences. Staff included clinicians and non-clinicians, as well as peer and non-peer professionals. The following table provides an overall summary of nine programs in the Outreach Initiative.

This guide describes important lessons learned in developing, implementing, and evaluating these interventions to engage and retain PLWHA in medical care. At the start of this initiative programs faced several common challenges. First, programs charged with the role of engaging and retaining clients in HIV care needed to explain this role to other providers in the continuum of care in their communities and work hard to establish the relationships and mechanisms
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to generate referrals. Second, programs needed to define and identify their target populations in order to devote their limited resources to reach those individuals with the highest risk of non-engagement in medical care. Third, many programs needed to retrain staff who previously provided traditional outreach and HIV prevention education in order to develop skills needed to motivate clients to seek HIV medical care and help them navigate the care system.

Obtaining partner buy-in, establishing clear roles and responsibilities for staff and partners, streamlining the intake and referral processes, and being involved at strategic policy levels both at the community and agency level are all critical steps in coordinating services and allocating appropriate resources to work with hard-to-reach HIV-positive populations.

This also required training supervisors and managers to support and supervise the staff in their new roles. Finally, one of the biggest challenges was setting up tracking and quality assurance systems to show whether the programs were working to engage and retain people in medical care.

Common themes
Some of the common themes that emerged across programs, and should be considered by any program regardless of intervention design, include:

Developing a niche in the community and developing strong sustainable partnerships
Case studies from the Konnect II Client Advocacy Program of People of Color Against AIDS Network (POCAAN), the CareLink Program of the Cascade AIDS Project, The Fenway Institute, and Drew University Mobile Health Outreach Project/UCLA present several important lessons on steps that need to be taken when developing and implementing new programs. Obtaining partner buy-in, establishing clear roles and responsibilities for staff and partners, streamlining the intake and referral processes, and being involved at strategic policy levels both at the community and agency level are all critical steps in coordinating services and allocating appropriate resources to work with hard-to-reach HIV-positive populations.

Using clinic or program data to develop criteria to identify hard-to-reach populations in need of HIV medical care
All community-based organizations and clinics receiving CARE Act funds are working with underserved populations in need of HIV medical care, however the demand for services overwhelms the supply of services. With limited funds, most organizations often need to target resources to specific populations. Whitman-Walker Clinic and the Well-Being Institute provide concrete examples of how to identify and target resources to the most vulnerable populations living with HIV at risk of dropping of HIV care. They describe their experiences analyzing past client data through clinic chart reviews or client surveys in order to help target resources to those most at risk of not seeking care.
Adapting existing program operations to include refresher training, close supervision, and team building

Finding and serving hard-to-reach populations requires adjustments to traditional service delivery operations of community-based organizations and clinics. First it is important to allocate sufficient staff resources to work with these populations. The section, “Staff Strategies: Perspectives from the Field,” examines the skills necessary for new and existing staff to engage and retain hard-to-reach HIV-positive individuals. The Horizons Project of Wayne State University and the Caring Connections Program of the University of Miami describe their experiences with training staff and implementing programs to promote positive behavior change in order to retain HIV-positive clients in medical care. Other system-level changes include establishing lines of communication across departments (such as case management and medical staff) to build a team approach. It is also important to implement a continuous feedback and supervision system; offer refresher trainings; and develop manuals, procedures, and other resources for all staff members and partners involved in working with clients.

Implementing quality assurance systems and conducting periodic program evaluation

Documenting program services and reviewing program goals is essential to understanding whether the program is meeting its goals to engage and retain hard-to-reach populations in care. Project Bridge of The Miriam Hospital and the CareLink Program of the Cascade AIDS Project offer suggestions for setting up systems to track services provided to clients and ways to monitor and evaluate your services. Quality assurance systems and periodic evaluations can help each program make adjustments to services in order to improve the ability to meet client needs and advocate for new client services.

How to use the guide

This guide is designed for program planners/directors, front line staff, and policy makers. It provides concrete activities and recommendations from nine programs in the HRSA/SPNS Outreach Initiative for designing, implementing, and evaluating programs to engage and retain PLWHA in care. Each section identifies a specific challenge confronting programs and describes strategies to address these challenges and promote engagement and retention of hard-to-reach populations.

The guide contains a series of case studies from each site participating in the HRSA/SPNS Outreach Initiative. The table in this section provides a quick reference of the themes addressed by each program. There is a list of contact information for each site to learn more about their programs, and the appendices include examples of forms and tools used by these programs. For example, Appendix 1 includes an outreach encounter form used by HRSA/SPNS programs to document and evaluate their activities with clients.

We hope this guide will assist other organizations and clinics to improve the quality of their services and enhance their ability to engage and retain people living with HIV and AIDS in care.
Building a niche in the continuum of HIV services to find and connect people living with HIV and AIDS to care

CareLink Program, Cascade AIDS Project Portland, OR

Goal of the intervention
CareLink, a program of Cascade AIDS Project (CAP), is an outreach and advocacy program whose goal is to identify people living with HIV/AIDS (PLWHA) who are out of medical care (or at risk of falling out of care), link them to medical and case management services, and provide them with support to remain and be successful in care.

Organizational setting and partnerships
The Title III HIV primary care clinic, the Centers for Disease Control and Prevention (CDC)-funded HIV Community Testing site, the County Corrections medical unit, the hospital-based HIV primary clinic that receives Ryan White funding, and the HIV case management program.

Target client population
The CareLink program targets two populations: hard-to-reach PLWHA—those who struggle with issues related to mental health, substance abuse, low socioeconomic status, and homelessness—and Latinos, whose main barriers to HIV care are related to language and culture.

Services provided/intervention type
CareLink’s multi-tiered approach is a combination of street outreach, community outreach, and group education and is based on a combination of theoretical models including the Transtheoretical Model/Stages of Change, the Health Belief Model, and the Social Network Theory. The CareLink Program is often the first point of contact for PLWHA who are in the process of accessing services. Clients come into contact with CareLink staff through corrections, HIV community testing sites, street outreach, peer referral, or through other HIV and non-HIV providers. Staff assess clients’ current level of engagement in HIV care and other social services, barriers to accessing those services, and readiness to engage in services, at baseline and continually throughout participation in the program. The program is grounded in a strong staff/client relationship and program staff develop individualized client-centered goal plans to guide their work with clients. Program staff use Motivational Interviewing techniques to move clients along the readiness continuum.
until they are ready to engage in medical care. Another key function of the program is to educate clients about HIV, the service system, self advocacy, and risk reduction, fostering clients’ sense of empowerment and ability to transition into the established HIV case management system. A special focus of the CareLink Program in Phase II of the HRSA/SPNS Outreach Initiative has been on health literacy and its role in successful care engagement, including a quarterly five-week group education series.

**Staff requirements**

Peer involvement is another key component of the CareLink Program. The CareLink team includes a combination of peer and non-peer outreach workers and advocates, bringing a more personally based perspective and experience to the intervention.

**Local evaluation results**

Preliminary results between baseline and post 12-month intervention found the following significant changes:

- 93% had a regular provider
- Increase in the number of primary medical visits reported from chart records from 2.5 to 3.4 visits*
- Reduction in the mean number of emergency room visits from 1.48 to .68*
- Reduction in the mean number of missed appointments from 1.13 to .84
- Increased percentage of participants with undetectable viral loads from 22% to 43%*

* p = 0.00
Cascade AIDS Project (CAP) is the fourth largest AIDS Service Organization in the western U.S. with an annual budget of $4.4 million. Its mission is to prevent HIV in youth and adults at highest risk; support men, women and children with HIV/AIDS and their families; and advocate for an effective community response to the epidemic. CAP’s core services include: HIV prevention education, housing and employment services, services to HIV-infected and affected children, benefits assistance, and a statewide AIDS hotline. CAP has a special initiative to increase prevention education and services in communities of color. CAP is not affiliated with a medical site, nor does it provide HIV case management services.

The CareLink Program at CAP began in March 2001, with funding from Title I of the Ryan White CARE Act, to provide outreach and advocacy. The guidance for CareLink activities was very specific: the program needed to identify people living with HIV/AIDS (PLWHA) who know their HIV status but are not in medical care and link them to care and case management services. CareLink was not only a new program, but also a new concept in the Portland area. It was not a case management program, yet the advocacy component looked a lot like case management. It was not a prevention program that conducted outreach to people of unknown HIV status to bring them into counseling and testing, yet the program was charged with conducting outreach. At the same time, the program needed a mechanism to identify HIV-positive individuals who were out of care. The program began with three major questions: How do we identify those who are not connected to services but who do know their HIV status, especially if they don’t want to be found? Where do we look for them? How do we get them to engage in services?

**Challenge: Finding the hard to reach**

After realizing that roaming the streets searching for out-of-care PLWHA was not a cost-effective way to identify members of the target population, another strategy was needed. Developing a niche for the program in Portland’s continuum of HIV care became a top priority. Without buy-in from other providers, we would not be able to find the clients the program was charged with locating, nor would the program staff be able to help them access HIV medical care, case management, or other services. To obtain this buy-in, we needed to make a case for how the program could fill a gap in the service continuum and demonstrate how these services could assist other providers in their work with clients, resulting in a stronger, more complete continuum of care. Below we describe how CareLink addressed this challenge.

The role of the CareLink Program in Portland’s service continuum is to provide short-term, outreach-based intensive services to out-of-care PLWHA. This service is needed because at-risk clients are assigned to case managers after they choose a medical provider. Thus, assisting clients in the process of accessing medical care is not a function of the case management program. In addition, the case management program does not have the capacity to proactively track clients who miss appointments and conduct outreach to clients who have missed multiple appointments.

*Identifying key partners and explaining our niche role*

The most important relationships developed in the local HIV service continuum were with the following programs:
The CDC-funded HIV Community Testing site—to obtain referrals of newly diagnosed individuals who were at risk for non-entry into care

The Title III HIV primary care clinic and a hospital-based HIV primary care clinic that serve low-income individuals—to establish linkage to care relationships

The County Corrections medical unit—to obtain referrals of PLWHA who were released from incarceration

The HIV case management program—to obtain referrals of PLWHA who had dropped out of medical services or were at risk of leaving care, and to create a case management linkage to care for individuals with no case manager

At the program’s inception, the Program Manager and outreach and advocacy workers met with key staff at all levels of both HIV and non-HIV service providers. Although CAP as an agency had established contacts with all of these organizations, CareLink was a new kind of service that needed to establish stronger relationships at both the administrative and direct care levels in order to ensure success of the program. CAP staff attended staff meetings at all partner agencies (and many others) to provide information about the new service. Partner organizations were given program outreach materials, a program fact sheet, and a flow chart showing how clients could enter the program.

Establishing clear roles and responsibilities and accountability mechanisms

After the staff presentations, Memoranda of Understanding (MOU) were developed with each program. To obtain buy-in from each program it was important to build the relationship with the existing programs from their perspective since CareLink was entering their “turf.” This was an important part of the MOU development. The MOUs specified CareLink’s role and relationship with each program, including how referrals were to be made. The formal relationships outlined in the MOUs increased the accountability of direct service staff at partner agencies to collaborate with the CareLink Program in the ways described in the agreements. As part of the process of developing the MOUs, specific contact people for each agency were identified.

Building and maintaining relationships with key partner programs and staff

Once the MOUs were signed, it was important for all CareLink staff to build strong relationships with key staff members at each of our partner organizations. The Disease Intervention Specialists, who deliver all HIV-positive results for the community HIV testing site, requested that all CareLink personnel attend their staff meeting to develop a joint referral process. This was a key relationship-building process because staff from both programs spent a good deal of face-to-face time developing the referral process and getting to know who would be receiving a referred client during the very sensitive time of receiving an HIV diagnosis. At the client’s request, CareLink staff members are now able to attend appointments that are scheduled to deliver seropositive test results. This process also helped the Disease Intervention Specialists understand which clients would be appropriate for outreach and advocacy services as opposed to direct referral to medical care and case management.

Developing a relationship with Multnomah County Corrections Department was less of an obstacle than expected. Because the medical unit is part of the Multnomah County Health Department, it was pos-
Making the Connection

It is essential that the local HIV Title I Planning Councils—which inform how dollars are spent with local Eligible Metropolitan Areas (EMAs)—see these types of “care outreach” programs as an integral part of case management programs in order to continue to reach those needing an alternative approach to effectively engage in long-term HIV care.

Sensible to bypass the correction system staff entirely and focus on developing a relationship with the medical staff. When medical staff identify a new client or when an established client is incarcerated, they notify CAP outreach and advocacy staff. CAP staff then go to the correctional facility where they are greeted by medical staff and escorted to the medical unit to meet with clients and talk to the corrections system medical providers.

At the Title III clinic where the HIV case managers are located on site, CAP staff work closely with case managers and clinic office staff to make appointments for clients or to ensure clients have been able to schedule paid for through Ryan White CARE Act Title III funds.

Linking outreach and case management to streamline the intake process, coordinate release of information, and establish consistent communication with key personnel

The case management system in Portland is linked to medical sites. PLWHA are assigned case managers based on their acuity score (level of needs) and where they go for medical care. A single organization hires, trains, and deploys all the case managers regardless of the medical facility in which the case manager works. For CareLink to be successful, a way was needed to reach clients who dropped out of care and who may have also dropped out of case management services. Strengthening the relationship with the case management system was an important step in this direction because the case managers had vital locator information. Shortly before the program began, a joint intake process was developed between the case management program and CAP that included an exchange of information between the two agencies. This meant that clients who signed the joint release and were lost to follow-up in case management services could be referred to CareLink for outreach, and clients who first came in contact with CareLink received an intake for case management services.

Because some CareLink functions overlap with case management, there is potential to duplicate services if communications are not clear and roles are not defined. At the beginning of the program many case managers questioned why CareLink was working with “their” clients. The program needed to establish a clear definition of roles, a consistent referral process, and a good communication...
strategy between CareLink staff and case managers. CareLink’s outreach and advocacy services are designed to be intensive, short-term, “pre-case management” services. CareLink serves a smaller number of clients than the HIV case managers since CareLink clients require much more time and effort to find and they have more complex needs. CareLink staff spend much of their time working to establish trusting relationships with clients and explaining HIV and how the care system works. These are activities that case managers, with their much larger caseloads, often do not have the time to do. Once a client is stable in care, the goal is help transition them into the existing case management system where they continue to receive services, but on a less intensive level. CareLink is not a program for people who are already connected with case management unless they are not participating in medical care. Yet, some clients might seek services from both programs, a duplication of effort that we cannot afford in times of limited resources. To avoid this duplication, clients who are enrolled in case management services and want CareLink services need a referral form from their case managers verifying that the client has fallen out of care or is at extremely high risk of dropping out of care.

The relationship between CareLink and case management is further strengthened at the monthly case management team meetings. The CareLink Program Manager attends these meetings that provide a chance to co-manage clients, monitor transitions, and identify new clients in need of outreach.

Getting involved with and informing Planning Councils
Our preliminary evaluation findings show that CareLink clients have improved health outcomes, decreased homelessness, and decreased high-risk behaviors. During CAP’s 2004–2005 fiscal year, the CareLink Program successfully connected 73% of out-of-care clients with medical care and helped retain 87% of at-risk clients in services. Traditional case management models are missing an outreach-based component grounded in harm reduction, strong relationship building, and meeting people where they are in their readiness to alter the health behaviors that may affect their successful engagement in services. Given the CARE Act’s move to heavily prioritize “core services,” it is essential that the local HIV Title I Planning Councils—which inform how dollars are spent with local Eligible Metropolitan Areas (EMAs)—see these types of “care outreach” programs as an integral part of case management programs in order to continue to reach those needing an alternative approach to effectively engage in long-term HIV care. CAP’s Program Manager currently holds a seat on this planning body, which has proven useful in positioning the CareLink Program as an integral part of Ryan White core services and in providing an effective format for highlighting the importance of the CareLink services and outcomes.

Conclusion
A successful care outreach program is dependent on the local social service system and, in particular, on the relationships between the CARE Act grantees and other service providers. Conducting a systemic and environmental assessment is a good starting point when trying to integrate a new program into an already existing continuum of services. This includes identifying gaps in services and determining what other service providers, clients, and stakeholders see as the biggest need for the community.
GOAL OF THE INTERVENTION
The Health System Navigation (HSN) intervention is primarily concerned with linking HIV-positive individuals, who are currently out of care or are sporadic users of care, with culturally appropriate primary HIV medical care and social services.

ORGANIZATIONAL SETTING AND PARTNERSHIPS
The HSN intervention is based at the Fenway Institute, the research, education and advocacy arm of Fenway Community Health. Health System Navigators (HSNs) are not limited to working within the Fenway Community Health Center, but conduct outreach and provide services at a number of agencies within the community.

HSN partner agencies are the Living and Recovery Community (LARC), an inpatient substance abuse treatment program for HIV-positive individuals; the Boston Living Center, a drop-in and social service center for HIV-positive individuals; the Fenway Community Health Center, a federally funded GLBT health center; and the Multicultural AIDS Coalition (MAC), a community-based AIDS service organization working with communities of color.

TARGET CLIENT POPULATION
The HSN target population is HIV-positive people, from traditionally underserved populations, who are not receiving consistent HIV primary medical care. HSN participants are current or recent injection drug users, ex-incarcerated individuals, sex workers, and men who have sex with men. Over half of the HSN participants are people of color.

SERVICES PROVIDED/INTERVENTION TYPE
Health System Navigators (HSNs) conduct outreach and provide services in the community, meeting their clients at home or at service agencies, and accompanying them to appointments. The skill sets of HSNs can either stand alone as the HSN job description or be incorporated into peer advocate, transitional case manager, or outreach worker job descriptions. HSNs conduct brief assessments, develop client-driven action plans, and work with clients to achieve their goals. The intervention is time limited.
and focused on helping people become stable in care through the establishment of more permanent relationships with culturally competent medical providers and case managers. Thus the HSN, working to complement case management services, may overlap with case management to a limited degree—such as making referrals—but only until such time as the client is receiving consistent culturally competent case management.

**Staff requirements**

Health System Navigators are individuals with similar backgrounds to the clients served and/or from the Boston Metro area. HSNs receive extensive intervention training through the five-day Health System Navigation Training Academy.

**Local evaluation markers**

Changes in participants’ health literacy measured by comparing self-report CD4 and viral loads with values recorded in the participants’ medical record.

**Local evaluation results**

Between baseline and post 12-month intervention, participants reported:

- The number of contacts with case managers (face to face or telephone) increased from 14 to 18 in the past 6 months
- The percentage of participants reporting a barrier to care due to health beliefs fell from 55% to 29%
- The percentage of participants taking HIV medications increased from 63% to 73%
- The percentage of participants with an undetectable viral load increased from 65% to 74%
- The percentage of participants attending 2 or more medical visits for HIV in the last 6 months increased from 65% to 82%*
- The percentage of participants having 0 or 1 visit in the last 6 months decreased from 35% to 18%*
- Reduction in the number of missed visits from 1.31 to .53*

* p ≤ .05
Fenway Community Health is a non-profit corporation in Boston, Massachusetts, with two major divisions: the federally qualified Fenway Community Health Center (FCHC), known for its excellence in HIV and other LGBT health care since the early 1980s, and The Fenway Institute (TFI), dedicated to ensuring the best health care for the diverse LGBT community. The Fenway Institute is a national interdisciplinary center of excellence that includes a data center, performance areas for research and evaluation, training and education, and health policy advocacy. TFI developed, implemented, and evaluated a Health System Navigation (HSN) intervention in Boston, a promising approach to assist HIV-positive individuals from underserved communities in gaining access to HIV care and related services. A core characteristic of the intervention is its delivery by community members from populations with the highest rates of new HIV infection. Health System Navigators (HSNs) proactively establish relationships with HIV-positive individuals who are either not receiving or are unstable in HIV care and work with them to reduce barriers and gain access to the HIV care they need. Health System Navigation is a community-based intervention: while HSNs are employed through an agency, they spend much of their time working with clients at other agencies and in the field, assisting them with paperwork, overcoming language barriers, developing clients’ self-advocacy skills, and accompanying them to appointments.

**Challenge: Linking different programs to ensure a continuum of HIV care**

The HSN intervention was developed by TFI in conjunction with the Multicultural AIDS Coalition (MAC), a community-based organization in Boston serving communities of color. During an initial planning phase, it was determined that a community linkage model was the most appropriate strategy to use in Boston to reach underserved HIV populations with the highest rates of new infection. As originally conceptualized, the intervention would span the continuum of HIV services from case finding to counseling and testing, through connection to and stabilization in HIV primary care. The original intent was to link two different interventions—one at TFI/FCHC and the other at MAC—to implement a continuous model of outreach, prevention education, counseling and testing, and access to HIV care and treatment.

To implement this model TFI worked closely with FCHC, our clinical division, and formed partnerships with four other community agencies that serve:

- Ex-incarcerated individuals
- Current or recent injection drugs users
- Men who have sex with men (MSM)
- People of color

As originally conceptualized, the intervention would span the continuum of HIV services from case finding to counseling and testing, through connection to and stabilization in HIV primary care. The original intent was to link two different interventions...
A social service and drop-in center for HIV-positive individuals

Interventions that reach out to populations at high risk of HIV—bringing people into HIV counseling and testing, and then linking those who test positive to HIV care and treatment—are important components of the continuum of HIV care. Our intent was to contribute toward a more fully realized continuum of care by filling critical gaps in the system, and we conceived Health System Navigation as a bridge across various gaps in the existing system. However, the requirements of one funder to demonstrate testing numbers and seropositivity rates and a second funder to demonstrate recruitment of HIV-positive clients and their engagement in HIV primary care posed a serious challenge for this community-based collaboration. TFI needed to demonstrate linkage to care, and thus needed a base of clients who were HIV-positive but not connected to care. MAC, as the lead agency on the CDC-funded Social Networks Demonstration Project (SNDP), could only deploy HSNs for case finding and HIV testing and was unsuccessful in obtaining permission from the state health authority to modify the activities of prevention specialists to incorporate the HSN approach. Thus, MAC was unable to supply a client base for TFI’s intervention.

As the project got underway, it became increasingly apparent that the core collaboration between TFI and MAC, as initially conceptualized, could not work within the context of these competing grant requirements.

The unique role of Health System Navigation in improving engagement and retention in HIV care

TFI operationalized the HSN intervention to ensure that linkage to HIV care remained a primary focus. Major needs identified at the outset of the project were for coordination and data sharing among HIV primary care and social service providers and for services that would help to stabilize people into HIV care. Case managers are often tied to a single agency but, while they may refer clients to other agencies that provide specific services, case managers are rarely able to accompany clients to these off-site appointments. On the other hand, HSNs are completely mobile and able to support case management by ensuring that clients follow through on referrals by accompanying them to appointments and assisting clients in self-advocacy. HSNs frequently accompany clients to appointments for housing, benefits, and medical care; assist clients in developing self-advocacy skills; and provide services through their SNDP. This decision was successfully implemented, resulting in more effective operations for both. The collaborative effort was continued at a reduced level, as TFI staff provided on-site evaluation and technical assistance for data management to MAC staff on their HSN project (SNDP).
In the baseline to 6-month interviews, clients [with a HSN] reported more frequent case manager contacts, as well as fewer missed appointments and emergency room visits. Fears of being stigmatized due to HIV and/or sexual minority status were reduced.

Local evaluation results provide initial evidence of the acceptance and effectiveness of the intervention. Much more than 50% of the baseline population was retained at the 12-month point. In personal interviews, clients reported a great deal of satisfaction with their HSN experience, with specific appreciation for the helpful and supportive nature of their relationships with Health System Navigators. After receiving the intervention, they reported a statistically significant reduction in unmet service needs and increased engagement with their HIV care providers. In the baseline to six-month interviews, clients reported more frequent case manager contacts, as well as fewer missed appointments and emergency room visits. Fears of being stigmatized due to HIV and/or sexual minority status were reduced.

Translation assistance. HSNs also spend a significant portion of their time delivering services via the telephone, coaching people about how to talk to their doctors, providing emotional support, and coordinating referrals.

Use of HIV medication increased as well. These early results are very promising, increasing confidence that HSN may indeed prove useful in assisting HIV-positive individuals to become engaged and retained in HIV care and, by extension, to build bridges over gaps in the continuum of HIV care.
Strategies for sustainability

Three core strategies have been used to develop Health System Navigation as a sustainable intervention to provide underserved populations with access to HIV care and related services:

1. Foster stronger relationships among community HIV/AIDS service providers
2. Create a replicable training program for interventionists
3. Integrate HSN into FCHC’s standard of care for hard-to-reach populations, if found effective during the HRSA/SPNS Outreach Initiative study period

Fostering stronger relationships among community HIV/AIDS service providers

HSNs in the field circumvented the need for more coordinated city-wide services by leveraging preexisting interagency relationships among Fenway Community Health, the four partner agencies, and contacts the HSNs brought to their work from previous employment in the Boston area. This flexibility on the part of HSNs facilitated client navigation through a diverse set of connections with case management, housing and other client advocacy staff. Working from these initial contacts, the HSNs forged strong relationships with individuals at non-partner service-providing agencies in the metro-Boston area. These agencies provided clients services such as: nutrition information and food bank services; utility relief services; housing advocacy and case management for Spanish-speaking clients; comprehensive case management, HIV information, transportation assistance and rental assistance; and kitchenware, bedding, clothing and household necessities for people in need, including newly housed individuals. While the creation of a robust network of local providers is still in the early stages, the flexibility and networking of the HSNs have been instrumental in laying the ground work for increased interagency collaboration and in introducing HSN as a value-added service across Boston.

Creating a replicable training program for staff that provides transferable sustainable skills

Project staff created the Health System Navigation Training Academy, an intensive, five-day, professional training workshop that equipped outreach workers from various agencies to implement the HSN intervention in their current positions. By developing the HSN intervention as both a job description and a skill set, we were able to lay groundwork for a sustainable inter-

By developing the HSN intervention as both a job description and a skill set, we were able to lay groundwork for a sustainable intervention not only within FCHC, but also with promise for the larger HIV service-providing community.

The first Health System Navigation Training Academy was well received and added to the portability of the project by providing a replicable curriculum and accompanying
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The Academy also helped TFI to meet several project sustainability goals. In these ways, the HSN Training Academy strengthened the potential for a sustainable intervention to expand outreach to HIV-positive out-of-care individuals and communities.

- One month after Part I of the Training Academy, over 70% of the trainees reported using aspects of the HSN intervention in their daily work.
- A community forum held the day before the Training Academy introduced the intervention to service providers across the city. As a result, agencies are using the term Health System Navigation and understanding the concept.
- There is a growing awareness among core agencies of the value of a cooperative model.
- The HSN terminology and basic components have been picked up and used in developing new grant applications and in modifying services in other Boston-area community-based organizations.

**Interviews with former patients indicated that more than 10% of HIV-positive medical care patients lost to follow-up each year would meet the eligibility criteria for the HSN intervention. These results have served as a useful guideline and an incentive for health center management to incorporate the HSN model into the FCHC standard of care.**

We have taken the first steps to incorporate HSN into the standard of care at FCHC. The three HSN interventionists currently working within TFI frequently coordinate with medical, mental health, and social work staff at the Health Center. Interviews with former patients indicated that more than 10% of HIV-positive medical care patients lost to follow-up each year would meet the eligibility criteria for the HSN intervention. These results have served as a useful guideline and an incentive for health center management to incorporate the HSN model into the FCHC standard of care.

One HSN is a part of the Massachusetts Club Drug Initiative’s New Champions program at Fenway. New Champions makes use of a peer-based model to decrease club drug use among MSM in the Boston area. As part of this intervention, New Champions staff and some peer volunteers informally incorporate facets of HSN into their work at designated MSM night clubs, such as Brief Motivational Interviewing to nudge clients towards seeking treatment services, and Stages of Change and Harm Reduction strategies to meet clients where they are and assure that the services provided meet current client needs. TFI has also worked with partners on CDC and Massachusetts Department of Public Health funded grants to adapt HSN to work with uninfected patients.

**Conclusion**

Moving forward, The Fenway Institute will seek grant funding to expand Health System Navigation services to other populations experiencing significant barriers to health care, including transgender individuals,
substance users, and people with serious mental illness. In May 2006, TFI was awarded a grant through the Boston Public Health Commission to conduct outreach to marginalized populations. The Prevention Navigation project will continue HSN efforts to increase the health and well-being of MSM of color and transgender individuals, marginalized groups at the highest risk for HIV infection and transmission. Health System Navigators will work with these individuals to overcome whatever barriers interfere with their ability to receive needed medical care and to find solutions for unmet needs, proactively assisting them to navigate available healthcare and social service resources. Funds have been requested from the federal Substance Abuse and Mental Health Services Administration in order to apply HSN services to better integrate substance abuse and medical services within the Fenway Community Health Center. At this juncture, more work needs to be done to strengthen interagency coordination and prepare potential partners for data coordination activities. Additional funding will be sought by TFI to more rigorously test HSN effectiveness with individuals and to continue expansion of the HSN model as a community-wide intervention.
Goal of the intervention
Engage and retain women in HIV-related primary care.

Organizational setting and partnerships
Well-Being Institute is a community-based organization located in Detroit, Michigan, which provides nursing outreach services and is partnered with Detroit Medical Center, Division of Infectious Diseases, to engage and retain women in HIV primary care.

Target client population
HIV-infected women, who are predominantly African-American and have a history of substance abuse and mental illness. The program specifically targeted women who were loosely connected to care as defined by:

» Going more than four months without an HIV medical appointment
» Reported having problems keeping HIV medical appointments
» Reported missing one or more HIV medical appointments in the past year
» Reported having no scheduled HIV medical appointments

Services provided/intervention type
Women assigned to the Extended intervention group received extended nursing outreach services such as home visits, accompaniment to the clinic and counseling, and transportation to the HIV clinic for six months. After that time, they received only Brief intervention services (transportation to health care appointments) for the next six months. The women in the Brief intervention group received only transportation to their clinic visits for 12 months.

Staff involved in the intervention
Nurses
Local program results

For the Brief intervention group (n=57) between baseline and post 6-month intervention:

» Improvement in the mean number of medical visits per chart record from 1.33 to 1.47

» Increase in the percentage of women who attended some medical visits and reported no missed visits from 21% to 57%

» Reduction in the mean number of missed visits from 1.92 to .72

For the Extended intervention group (n=48) between baseline and post 6-month intervention:

» Improvement in the number of mean medical visits per chart record from 1.08 to 1.6

» Increase in the percentage of women who attended some medical visits and had no missed visits from 9.8% to 51.4%.

» Reduction in the mean number of missed medical visits from 1.68 to .90
The Well-Being Institute (WBI) has provided nursing outreach services to hard-to-reach women living with substance abuse and/or HIV infection in Detroit, Michigan, for the past 23 years. WBI operates a nursing outreach clinic in inner city Detroit from which it conducts research to test models of nursing outreach services. Most recently, WBI focused on developing ways to engage and retain women in HIV-related primary care who are lost to follow-up or are loosely connected to care. WBI outreach nurses provide “medical outreach,” which differs from case management or other outreach because nurses provide medical and health-related education to help women see a need to reconnect themselves to HIV medical care. This outreach is conducted in client homes in the community and includes accompaniment to medical visits as requested by clients.

Challenge: Allocating appropriate staff resources to engage and retain HIV-infected women in care

In these days of shrinking healthcare funding, WBI staff realized that extensive outreach nursing services could not be provided to all the clients with whom they come in contact. From years of experience, WBI’s nursing staff sensed that not every woman who is lost to follow-up in primary care clinics needs the same intensity of services to reengage and remain in HIV primary care. While some women need extensive medical information and education about their illness and the importance of health care in order to reengage in health care, requiring many home visits and significant staff time, some women merely need transportation (and therefore much less staff time) in order to reengage in care. In Detroit, the public transportation system is woefully inadequate and prior studies have identified it as a major barrier to care for low-income women without cars. Neither the major medical center nor the private physician practices to which women are assigned under the Medicaid managed care program are easily or reliably accessible by public transportation. Buses are infrequent and they do not run on schedule, and during the winter months people often have to wait an hour or more outside in frigid temperatures for public transportation.

The challenge for WBI staff was to develop a practical, effective, and humane way to determine which women need more services and staff time, and which women could meet the same reengagement-in-care goal while receiving fewer services taking less staff time. Under the HRSA/SPNS Outreach Initiative, WBI first identified criteria that described a woman’s vulnerability for non-engagement in care; and then used these criteria to develop an algorithm to determine which of two levels of nursing outreach service delivery was most appropriate: a brief intervention or an extended intervention. It was hoped women in each of the study groups would increase the number of visits to routine HIV-related primary care providers. The ultimate goal was to create a more effective use of resources in order to engage and retain women in HIV primary medical care using just the staff time and program resources needed to retain women in care.

Selecting an HIV clinic partner to identify out-of-care HIV-infected women

WBI has a long-standing relationship with the HIV primary care clinic at the Detroit Medical Center (DMC), which serves many HIV-positive women who also have co-occurring diagnoses such as addiction or mental illness. As prior collaborators in
research studies, WBI and the clinic have access to confidential information about their shared clients. The DMC’s Clinic Director was interested in having a partner that could conduct outreach to encourage patients’ return for their scheduled clinic visits. The director also appreciated the fact that WBI nurses attend primary care medical visits with the women and translate the medical plan of care when women are confused about what the physician is recommending for them.

Developing the algorithm
Prior to implementation of the intervention, WBI examined the socio-demographic, care utilization, and self-perception of well-being characteristics of 75 women enrolled in a previous study who had not returned for a scheduled visit at the DMC clinic in the last 4 months. The women ranged in age from 21–66 years, 95% were African-American, and only 4% were employed. Analysis was conducted to determine which vulnerability variables were associated with the following outcomes: emergency room visits, hospital admissions, and well-being. This analysis identified five factors associated with these outcomes, in the following order:

1. Mental illness
2. Heroin use
3. Exchanging sex for money or drugs
4. Unstable housing
5. Crack cocaine use

Alcohol use in the past 30 days, physical harm in lifetime, and money spent for drugs in the last 30 days were not included in the final group assignment criteria because they did not meet the specified requirements for selection, based on their lack of association with either category of health services admissions.1

Conducting study recruitment, group assignment, and the intervention
The next step was to evaluate whether this algorithm correctly identified the most vulnerable women, and if by targeting intensive services we could reengage and retain both groups of women in HIV-related primary care. To enroll in the study women had to meet the criteria of being loosely connected with care, defined as: missed appointments

The challenge for WBI staff was to develop a practical, effective, and humane way to determine which women need more services and staff time, and which women could meet the same reengagement-in-care goal while receiving fewer services taking less staff time.

The program recruited 112 HIV-positive women to receive some level of program services for a total of 18 months. An intake interview was administered and all five predictors were recorded. Women who reported mental illness or heroin use were assigned to the Extended intervention group. Women with no kept appointments in the prior 4 months, no current appointment, self report of trouble keeping appointments, or newly diagnosed and no receipt of HIV medical care. Program participants were recruited through prior connections with WBI, being lost to follow-up at the clinic, testing positive at the WBI HIV testing program for women in the sex industry, publicity through local HIV support groups, and through word of mouth.

The program recruited 112 HIV-positive women to receive some level of program services for a total of 18 months. An intake interview was administered and all five predictors were recorded. Women who reported mental illness or heroin use were assigned to the Extended intervention group. Women
with other vulnerability factors but no mental illness or heroin use were assigned to the Brief intervention group for practical purposes because each of the nurse outreach workers needed evenly sized groups to balance their caseloads. However, after a few weeks it was clear that about half the women had either mental illness or heroin use.

Women in the Brief intervention group only received transportation to their clinic visits during the three six-month periods. For the first six months, women assigned to the Extended intervention group received nursing outreach services such as home visits, accompaniment to the clinic, counseling, and transportation to the HIV clinic. For the next two six-month periods, the women received only the Brief intervention of transportation assistance.

**Results**

Early results support the efficacy of the criteria as a method for allocating nursing outreach services to maximize reengagement and retention for 112 women loosely connected to care in a HIV primary care clinic—but with a twist. The twist is our lesson learned.

We found that women in the Extended intervention group significantly increased their use of HIV primary care after six months of receiving intensive services. As expected, HIV medical visits decreased in the following six-month period when they started receiving only transportation services. The women were no longer getting the intensity of intervention needed to sustain their retention in care.

The Brief intervention group with only transportation maintained a connection to health care in the first six months of program services. However, in the following six-month period, women in the Brief intervention group significantly decreased their medical visits. It was expected that women in the Brief intervention group would be retained in care with just the transportation services.

We found that the vulnerability characteristics for some of the women assigned to the Brief intervention group changed over time. They either reported heroin use or gave answers implying mental health problems, thus signifying a need for more intensive services in order to be retained in health care. On the basis of heroin and mental health responses at six months, 24% of the original Brief group would have been eligible for the Extended intervention. At 12 months the percentage was 20%, and at 18 months the percentage was 24%. Since intervention levels were not adjusted during the study, the decrease in the mean number of medical visits for the brief group may be attributed to the change in eligibility levels. When the degree of vulnerability increased, a more intensive intervention may have been necessary to retain the women in health care. Needs changed, and some participants were not getting the new level of
service needed to sustain retention in health care.

**Conclusion**

Thus, major lessons learned are that (a) group assignment criteria can be used by outreach staff, even novices, to make the optimal use of scarce resources and limited staff time and still give women the level of service needed to engage and retain them in HIV-related primary care; and that (b) women need to be reassessed every six months to be sure their vulnerability characteristics and their level of intervention needs have not changed.

Women who have mental illness or use heroin need more outreach services to reconnect them to HIV primary care and to retain them in care; these two factors create barriers to seeking out and maintaining connection to the traditional health care community. Provision of the appropriate level of outreach services to connect and retain women in HIV primary care has been shown to increase the number of primary care visits, but women need to be reassessed using the group assignment criteria every six months to assure they are receiving the level of outreach intervention needed to sustain retention in HIV-related primary care.

**Notes**

1. For a detailed description of the statistical process, refer to *Predicting Optimal Level of Nursing Outreach Services for Women Loosely Connected to HIV Related Primary Care*, Andersen M. et al (2005).

**References**


The Retention Care Coordinator program: Adapting internal program services to retain the most vulnerable in care

Whitman-Walker Clinic
Washington, DC

Goal of the intervention
The Retention Care Coordinator Program (RCC) is a clinic-wide intervention to retain patients in HIV-related medical care.

Organizational setting and partnerships
Whitman-Walker Clinic (WWC) is a community-based health clinic in the metropolitan area of Washington, DC, and provides health care services to people living with HIV/AIDS and the broader community. The clinic provides HIV-oriented primary medical care, behavioral health services, legal services, and health promotion and disease prevention services in the community. WWC partnered with Georgetown University School of Nursing and Health studies for the design, implementation, and evaluation of all RCC program activities.

Target client population
HIV-positive persons at risk for falling out of medical care: communities of color, persons with a history of incarceration, and people in recovery.

Services provided/ Intervention type
The RCCs provided reminder phone calls to patients the day before their appointment, helped arrange transportation or child care, accompanied patients to medical appointments to help process and further explain the information people received from their doctors, provided treatment and medication adherence support, and helped patients navigate services either at the clinic or at other health care institutions within the District of Columbia metropolitan area. Patients eligible for the intervention study worked with a RCC and received services for either a six-month or 12-month period.

Staff requirements
RCCs are paraprofessionals who work primarily within the clinic as patient advocates, health educators, and health system navigators.
Local evaluation results

Patients who worked with a RCC had lower no-show rates for clinic appointments compared to other similar patients in the clinic who did not receive services.

» Reduction in the no-show rate from 36.5% to 30.6% (post 6-month intervention) and 29.7% (post 12-month intervention) at the Elizabeth Taylor Center.

» Reduction in the no-show rate from 34.2% to 22.6% (post 6-month intervention) to 26.4% (post 12-month intervention) at the Max Robinson Center.
For more than 20 years, Whitman-Walker Clinic (WWC) has provided medical and social services to people living with HIV/AIDS in Washington, DC, metropolitan area. Despite availability of HIV primary medical care, in recent years the appointment no-show rate for HIV-related medical services at Whitman-Walker Clinic has been as high as 30%, causing concern among medical providers regarding patient health and quality of life. The Retention Care Coordinator (RCC) Program is a clinic-wide intervention to retain patients in HIV-related medical care. RCCs are para-professionals who work primarily within the clinic as patient advocates, health educators, and health system navigators for those individuals identified as being at highest risk of dropping out of care after their first appointment at the clinic.

Challenge: Identifying the most vulnerable patients for dropping out of care and allocating resources to help them

The clinic faced several challenges in trying to reduce its no-show rate. The first challenge was identifying who were the most vulnerable patients for dropping out of care. The second challenge was finding a way within the clinic to target this group of patients, and then determine who among staff would work with these patients. Below we describe the steps taken by the clinic to address these challenges.

Analyze past or current clinic data to get a picture of the most vulnerable clients

With limited resources, the program could not provide retention care coordination service to every new patient at WWC. In an effort to better understand the current patient population, existing clinic data was used to gain an understanding of the characteristics of patients who are more likely to drop out of care. Staff members began by conducting a retrospective chart review of all new patients who entered the clinic over a six-month period to determine what combination of psychosocial and demographic characteristics of patients were predictive of dropping out of care after their first visit to WWC. Through statistical analysis, three factors were identified that—when taken together—were associated with non-retention in care: being non-Caucasian, being unemployed, and recent or current drug use.

Examining clinic systems and training existing staff

The next step was to develop a screening tool to apply to new patients to determine who might benefit most from the intervention. Then the clinic had to determine the most effective way to use the tool within the clinic system and among staff. The clinic’s intake center was identified as the key point for conducting a screen to identify new patients who were at risk of dropping out of care. Existing intake staff included the screen as part of the routine intake process. When every new patient came to the clinic seeking medical services, the intake coordinator entered codes for the three factors identified by statistical analysis.
Factors mentioned above (i.e., race/ethnicity, employment status, and drug use) into an Excel spreadsheet that contained factor weightings. A “likelihood score of dropping out of care” was automatically calculated. For the purposes of this study and to validate the algorithm, anyone with a probability of 75% or greater of dropping out of care was referred to the intervention.

The final challenge was to decide who would help these patients stay in care and how they would do it. Because existing case managers and social workers already carried high caseloads, they would not be able to devote sufficient time and attention to patients who needed the additional help to stay in care. We decided to create a new staff position called Retention Care Coordinators (RCCs). The RCCs were available to come directly to the Intake Unit whenever a new patient was identified to talk with the person about joining the program and the services that were offered. The RCCs provided reminder phone calls to patients the day before their appointment, helped arrange transportation or child care, accompanied patients to medical appointments to help process and further explain the information people received from their doctors, provided treatment and medication adherence support, and helped patients navigate services either at the clinic or at other health care institutions within the District of Columbia metropolitan area. RCCs also made referrals to social services and public benefit programs, but if patients had ongoing or persistent needs, RCCs would refer these patients to a case manager. If a patient missed an appointment, the RCCs followed up with the patient and tried to reschedule the appointment.

Training new staff in appropriate skills to work with vulnerable clients
Upon hire, all RCCs received a two-day training in the clinical aspects of HIV/AIDS; health literacy; poverty; abuse, neglect, and violence; homelessness; substance abuse; and communications. RCCs took part in extensive role-play scenarios to practice future interactions with patients. This training was essential for the RCCs, because as paraprofessionals they needed this additional support. During the project, RCCs participated in DC-based seminars and training programs that addressed ancillary medical topics and/or behavioral health issues. These additional workshops were useful since patients with a high probability of dropping out of care have extensive psychosocial (including mental health and substance use issues) and structural needs impeding regular utilization of care.

Establishing lines of communication and referrals between departments and staff
Acceptance of the use of the screening tool, as well as acceptance of the role of the RCCs among other clinic staff, was a gradual pro-
The success of the model is its focus on the patients at greatest risk of dropping out of care, and the use of a screening tool to identify these people. In addition, the program worked closely with current staff to identify how the RCC [Retention Care Coordinators] would complement and facilitate the roles and responsibilities of existing providers.

Addressing provider resistance to the new role of the Retention Care Coordinators

One of the duties of the RCCs was to accompany patients to all medical visits, both within the Clinic and to outside referral appointments for necessary care that could not be provided at Whitman-Walker. Medical providers were initially highly skeptical of the presence of the RCCs during patient medical visits because they felt the presence of an outsider would violate doctor-patient confidentiality. However, RCCs were present in the exam room only at the request of the patient, and excused themselves if at any time during the visit the doctor needed to perform an examination where the presence of the RCC would be inappropriate.

The initial resistance from medical providers was gradually reduced as providers began to trust the RCCs and realized the benefits of this intervention for their patients. For example, in a busy urban clinic where follow-up visit appointments are limited to 20 minutes, physicians and physician assistants appreciated the fact that other staff were available to help process medical information and treatment instructions with patients who needed more time for these activities. RCCs also participated in multidisciplinary team meetings when patients from their caseload were reviewed, and their input at these meetings was highly valued by non-project staff. After about six months, medical providers were approaching the RCCs to ask if they could help other patients that they felt could use additional support. This was not possible at the time because the intervention was being evaluated and was limited to new patients entering care at the clinic, but it may become a practice in the future.

Even with retention care coordination, not every patient has the skills or desire to engage in HIV primary health care. However, at a clinic where the overall no-show rate sometimes exceeds 30%, the no-show rate among this group of individuals who received retention care coordination was only 25%. Although 25% may be considered high for a no-show rate, if we take into account that the intervention targeted indi-
individuals who had a 75% or higher likelihood of dropping out of care altogether, it is fairly impressive.

**Conclusion**
The success of the model is its focus on the patients at greatest risk of dropping out of care, and the use of a screening tool to identify these people. In addition, the program worked closely with current staff to identify how the RCC would complement and facilitate the roles and responsibilities of existing providers. Having consistent communication and meetings with providers—both medical and case managers—was critical to the acceptance of the RCC. In the future and depending on available funds, WWC hopes to incorporate RCCs into the general clinic system operations.
Training and supervising staff in appropriate treatment delivery
Horizons Project, Wayne State University
Detroit, MI

Goal of the intervention
To find and connect HIV-positive youth to HIV primary medical care and to promote regular use of HIV care by HIV-positive youth who have previously received services but use them sporadically.

Organizational setting and partnerships
The Horizons Project is a community-based program affiliated with Wayne State University and the Detroit Medical Center.

Target client population
The program targets at-risk and HIV-positive youth who are of unknown HIV status, the newly diagnosed, those lost to follow-up from medical care, and sporadic users of medical care. There is no specific target based on race, gender, sexual orientation, or socioeconomic status.

Services provided/intervention type
The Phase II SPNS intervention was titled “Get Here, Get Down” and provided clients with a comprehensive continuum of HIV services including medical, ancillary, and prevention services (i.e., outreach, case management, mental health, transportation, peer support groups, etc.) in addition to a four-session motivational intervention (Motivational Interviewing/Values Clarification-MI/VC).

Staff requirements
Four existing staff members were trained to provide the intervention. Two were educated through high school and two through graduate school.
Local evaluation markers
To measure the effectiveness of the program at the local level, the program is using the number of times a client has seen an HIV care provider in the past six months. Additionally, we are using GAP scores (number of quarters containing one appointment), Readiness ruler (used to assess readiness to change pre/post intervention sessions), and self-efficacy (used to assess client’s belief in ability to change assessed at intake and follow up).

Local evaluation results
» 93% of youths were retained in care over a 12-month period (attended at least one medical appointment every 6 months)
» 77% of youths reported MI/VC intervention helped them understand the role of medical care
» 80% of youths reported they could develop a plan for keeping appointments
» 76% of youths reported they could live healthier with HIV/AIDS
» Staff, including peers, can be trained in MI interventions with adequate resources
» Peers are equally or more effective with adequate training and ongoing supervision
The Horizons Project is a community-based program affiliated with the Detroit Medical Center that engages and retains HIV-positive youth (aged 13 to 24) in medical care. For more than 10 years, Horizons has provided outreach, case management, and peer support services to at-risk and HIV-positive youth. In order to improve the engagement and retention of HIV-positive youth, Horizons found that greater emphasis on promoting behavior change was essential. To achieve this goal, staff members were trained in Motivational Interviewing (MI), an evidence-based intervention designed to improve readiness to change health risk behaviors. The staff members were chosen for training from existing peer level (high school education) and masters level (post-college education) prepared staff. Our objective was to find a cost-effective method to reduce sporadic use of medical care and promote healthy behaviors in HIV-positive youth. The results would be integrated into our standards of care for newly diagnosed and lost to follow-up HIV-positive youth.

Treatment specification and integrity of intervention delivery are essential for a valid evaluation and dissemination of an intervention model. As Kazdin (1988) has noted, however, the dissemination of treatments is difficult to achieve because treatment components are usually not described sufficiently to allow replication, and treatment integrity is rarely evaluated. To address this problem, Bickman and Noser (1999) recommend that service providers, particularly in the counseling field, develop and evaluate continuous quality improvement (CQI) systems (Deming 1986). CQI requires the development of data-based feedback systems that continuously monitor the behavior of organizational members (e.g., counselors, supervisors, administrators) and the associations between these behaviors and outcomes of interest (e.g., retention in care, adherence). The resulting information is then used to develop organizational strategies aimed at promoting those processes that are most predictive of favorable outcomes. Thus, CQI involves comprehensive measurement systems, continuous feedback mechanisms, and serious organizational commitment to quality improvement.

Challenge: Maintaining fidelity to the treatment model
During the implementation of the program, an established structure and process to promote staff fidelity to intervention protocols was needed. It was realized that the intervention must be delivered as designed in order to know if it was effective and to prevent drift to the old/original way of doing things (to ensure staff were doing Motivational Interviewing and not some other form of peer counseling). By providing clinical oversight and ongoing feedback from several sources, we established systems that would detect deviations from the model and...
Making the Connection

help staff make changes in their work that supported fidelity to the model.

**Developing manuals and procedures to share with staff**

The intervention approach was to utilize Motivational Interviewing to increase youths’ readiness to engage and remain in HIV primary care. The first step was to adapt MI for our particular target behavior (enrollment and retention in care), and to manualize this adaptation. We learned early on that the development and utilization of a manual was critical to initiating a new intervention in a consistent way and in formalizing training. We spent a significant amount of time in the first year tailoring the intervention protocol to our particular population and targeted behavior of enrollment and retention in care. The intervention was tailored to meet the needs of a young, urban, minority population with average to below-average literacy. This effort resulted in standardized session outlines, documentation forms, and client educational materials. When planning an intervention, time must be allotted for this process. Manual development is a process where the original content is edited over time as the intervention is implemented in the real world. Feedback of supervisors, counselors, and clients is critical to this process. Several of the tools used in the project are located in Appendices 2–5 (see Horizons Project GHGD).

**Providing training and feedback to staff**

The core training package for Motivational Interviewing begins with an initial two-day training with the following objectives: (a) familiarize counselors with the philosophy and spirit of MI; (b) describe the theoretical and empirical underpinnings of MI including the Transtheoretical (Stage of Change) Model; (c) describe the basic skills of MI including reflective listening, expressing empathy, developing discrepancy, and
Training procedures include slide presentations, structured discussion, role-play, and interactive formats. Following training, trainees must complete role-play practices with peer staff or former clients that are audiotaped for supervisor review.

Promoting change talk; and (d) provide counselors with role-play practice in the MI method. Training procedures include slide presentations, structured discussion, role-play, and interactive formats. Following training, trainees must complete role-play practices with peer staff or former clients that are audiotaped for supervisor review. MI counselors (chosen from peer and professional staff in the program) are not “cleared” to see clients until the supervisor is comfortable with the quality of the role-plays. In general, we found that receiving a clearance took anywhere from four to six weeks. It is assumed that counselors have basic training in HIV-related issues before training in Motivational Interviewing.

Conducting regular clinical supervision
Counselors meet weekly for 120 minutes of group supervision with a certified MI trainer. This supervision is ongoing, and counselors are required to attend as long as they are seeing clients. Supervision focuses on promoting adherence to MI method, including: practicing advanced skills such as rolling with resistance (i.e., how to manage clients who are reluctant to change behavior); developing solutions to difficult clinical situations (i.e., clients crossing boundaries with staff); and designing plans to overcome any barriers to obtaining strong fidelity to the model. Counselors bring audiotapes of sessions with their patients to meetings with their supervisor for review and discussion. A possible barrier is that staff members do not prioritize supervision time. This prioritization must come from the top down. Administrative supervisors must give clear messages to staff that supervision is a priority, and that staff will not be allowed to conduct the intervention without it. Administrative supervisors must also decide if other duties should be reassigned so that staff members have the time to dedicate to training and quality improvement.

Monitoring performance through coding of audiotaped therapy sessions
One audiotape per counselor per month is randomly selected for coding by an objective facility in New York City. The coding system has been developed and tested by the original MI research group. The coding yields objective ratings of treatment fidelity from unacceptable to beginner to expert proficiency along several dimensions. In other programs, review of tape codings by a certified MI counselor was equivalent to clinical supervision (meeting with a supervisor for review of taped sessions with clients) in achieving good outcomes, though the combination was most effective (Bien et al. 1993). The clinical supervisor also reviews tape codings so that immediate quality improvement efforts can be initiated if codes reveal concerns. Alternatively, counselors receive positive feedback when coding is acceptable. Codes reveal areas of strengths and weaknesses that allow both the counselor and the supervisor to tailor supervision and ongoing staff trainings. Having quality coders available (who have shown evidence of interrater reliability)
and contracts/agreements regarding quick turnaround time for quality improvement efforts are critical.

**Conclusion**
Although AIDS Service Organizations (ASOs) and community-based organizations (CBOs) may not benefit from the financial resources of a large university or medical center, for outcomes to be attributed to the intervention, resources must be allocated up front. For example, tape coding may not need to occur at the rate of one tape per therapist per month, but it must occur prior to counselors receiving “clearance” to begin the intervention. Additionally, tape coding at least once per quarter (in lieu of weekly supervision if not affordable) will help ensure that counselors are not drifting from the intervention format (i.e., employing other therapeutic techniques). Finally, with adequate training and supervision peers are equally effective and more likely to be cost-effective in delivering evidence-based interventions.

In summary, treatment fidelity and quality assurance procedures are critical to implementing evidenced-based practice. These procedures ensure that the intervention is being delivered as designed and that outcomes have the greatest likelihood of being achieved. Sufficient time must be allotted for training, ongoing supervision, and quality improvement, and sufficient funds must be allocated for clinical supervision and quality assurance methods (e.g., tape coding). Without the evaluation of treatment fidelity and continuous quality improvement, outcomes that are achieved cannot necessarily be attributed to the intervention.

**References**


Retaining at-risk women in care: Incorporating a motivational intervention into a clinical setting

Caring Connections, University of Miami
Miami, FL

Goal of the intervention
Promote regular use of HIV care by HIV-positive individuals who have previously received services but use them sporadically (retaining sporadic users).

Target population
HIV-positive pregnant and non-pregnant women who are sporadic users of prenatal and primary care.

Organizational setting and partnerships
Two dedicated HIV prenatal and primary care clinics in the University of Miami/Jackson Memorial Medical Center, in inner-city Miami: the Prenatal Immunology Clinic of the Department of OB/GYN and the Special Immunology Clinic of the Department of Medicine.

Services provided/intervention type
Brief, intensive, scripted, four-session (two face-to-face, two telephone boosters), behavior-change intervention targeting healthcare services utilization behaviors. The intervention is based on empirically validated frameworks and strategies (Stages of Change and Motivational Interviewing) with a psycho-educational component and focused follow up. Content focuses on problem-solving skills enhancement (to boost effectiveness in negotiating system barriers), educational strategies (to enhance beliefs in the efficacy of regular medical care in deterring HIV disease progression), and motivational enhancement (to promote positive health services utilization behavior change). The intervention targets the next scheduled HIV medical care appointment and ongoing HIV health care service utilization in general.
Staff requirements
Clinical social worker (MSW), clinical psychologist, registered nurse or nurse practitioner, or similar, with supervision to ensure fidelity of intervention content and process if more than one staff member delivers the intervention.

Local evaluation markers
Target medical appointment (kept, rescheduled/kept, rescheduled/not kept, not rescheduled); changes in service utilizations patterns (number of appointments scheduled, kept, and missed); changes in client perceptions of primary care; changes in medication adherence and medication intentions; changes in perceived efficacy of HIV care (i.e., belief that seeing HIV doctor regularly will reduce likelihood of HIV-related health problems); changes in health status (physical, mental); changes in CD4 or viral load.

Local evaluation results
Comparisons between baseline and post 6-month intervention show the following significant changes among these sporadic users of medical care:

» 79.5% of participants kept the targeted post-intervention medical appointment

» More than half continued to keep all medical appointments (up from 11.5% at baseline)

» Reduced number who missed at least 1 appointment (41%, down from 88.5% at baseline)

» Reduction in structural/financial barriers and belief barriers (especially for appointment keepers)

» Worse baseline mental health (SF-12 scores) for those who continued to miss appointments post 6-month intervention identifies a subset needing additional help to comply with medical care
Caring Connections, a program for HIV-positive pregnant and parenting women in Miami, Florida, was designed to address the sporadic use of care by many of the women who received their HIV care at the University of Miami’s Jackson Memorial Medical Center. The program is a response to the dilemma of shrinking resources for psychosocial support services and the fragmentation of health care systems, both of which can undermine the ability of women with multiple challenges to remain in HIV primary care. Caring Connections sought to address these issues by incorporating into an existing primary-care clinic a means to enhance clients’ problem-solving skills and personal strengths in order to improve their ability to navigate the health care system themselves, and their motivation to do so. Thus equipped, clients are more likely to remain engaged in care.

The women enrolled in the Caring Connections program received their HIV-related primary care in one of two HIV clinics at the Medical Center—the Prenatal Immunology Clinic of the Department of OB/GYN or the Special Immunology Clinic of the Department of Medicine. Caring Connections focused on sporadic users of care, defined as women who had received HIV-related medical care in the past but had missed two consecutive medical appointments or had entered prenatal care in their last trimester of pregnancy. These women, mainly from poor minority communities, had multiple challenges, which led to their sporadic, rather than regular, use of HIV primary medical care. Nearly all had several children and caregiver responsibilities, most lived in overcrowded conditions, and many had a history of homelessness, trauma, and mental health concerns. Consequently, the Caring Connections intervention targeted women who were at high risk of dropping out of care.

The main aspects of implementing such an intervention—to enhance clients’ ability and motivation to navigate the health care system themselves, and thus remain in care—are described below, along with experiences in the process.

**Establishing clinic commitment to incorporate the intervention as part of clinic services**

The first step in implementing the intervention was to secure commitment and buy-in from both administrators and staff for the intervention to be delivered as part of regular clinic services. Nurses and nurse practitioners were identified as the appropriate staff for carrying out the intervention, a task that became part of their job descriptions. Training was provided to enhance staff understanding of the relational aspects of engagement and retention necessary to carry out the intervention, as well as to deliver a scripted intervention based on Stages of Change and Motivational Interviewing. The staff members that were trained were able to deliver the scripted intervention effectively.
Nonetheless, despite administrative and staff support and the staff’s ability to deliver the intervention, it could not be successfully carried out in the clinic as planned. Although nursing staff time was dedicated to this effort, it was scheduled as specific periods that had to mesh with other tightly scheduled clinic duties. However, it was found that staff time to deliver the intervention needed to be flexible in order to accommodate the erratic appointment-keeping behavior of the women identified to participate in the intervention, who by definition were unlikely to keep scheduled appointments. Due to other life demands, these women were frequently either late or no-shows in the narrow appointment windows that the nurses could offer. It became clear that to deliver the Caring Connections intervention, a dedicated staff person was needed who could be available to deliver the intervention whenever the women arrived at clinic.

Delivering the intervention and establishing a team approach to care

With a dedicated individual delivering the intervention, the Caring Connections staff formed an intervention team—apart from, but connected to, the clinic setting. The team members had various levels of training, as is the case within clinic settings, yet each formed a relationship with the client by interacting with her throughout the course of the intervention. Thus, the intervention team provided each client with a team of providers she could contact for help and advocacy at any time.

The Caring Connections intervention, an empirically validated behavioral approach, provided two face-to-face sessions and two telephone booster sessions targeting healthcare service utilization behaviors. The intervention emphasized problem-solving skill enhancement to promote the women’s effectiveness in negotiating system barriers, educational strategies to enhance beliefs in the efficacy of regular medical care for deterring HIV disease progression, and motivational enhancement to promote positive health service utilization behavior change. Booster sessions served to reinforce gains and attempt to restore a quick return to appropriate health services utilization behaviors following relapses.

Perhaps the strongest change mechanism within the scripted intervention was the combination of several Motivational Interviewing techniques (developing discrepancy, exploring decisional balance, and looking forward). In combination, these techniques revealed for participants the discrepancy between current behavior and outcomes and desired behavior and outcomes, the pros and cons of change (including costs of changing and barriers to doing so), and the long-term outcomes for themselves and others (“Where will you be five to 10 years from now if you do or don’t make behavior changes, and who will that affect?”). This
proved to be a powerful tool for penetrating denial in the majority of participants. Even so, system changes by treatment providers to encourage, validate and support these women are crucial for sustaining their behavior-change efforts to make more appropriate use of medical care.

Promoting attitudinal shift toward relational enhancement in all clinic contacts

Although the multidisciplinary team established in this program was not within the clinic, as intended, it proved to be a vital component for reinforcing intervention effects. Indeed, with resources shrinking for providing HIV health care, the women in this program—sporadic users of care—are those who are most likely not to receive services. They also are unlikely to receive attempts to facilitate behavior change in their use of medical care, largely due to lack of manpower and budgetary resources. Therefore, the overarching challenge becomes one of devising a behavior change mechanism and system that can be put in place for these women without additional funding and manpower for treatment providers—a tall order, but not impossible.

The importance of the relational connection established by each team member with the women in this program cannot be overemphasized as a tool for promoting adherence to appropriate medical treatment among sporadic users of care. Clinic environments—by necessity structured and time-oriented—are often at odds with the chaotic and survival-oriented lifestyle of sporadic users of care. If clinics are perceived by these women as unresponsive to their needs, sporadic use of medical care is a likely outcome. There is a shift necessary in staff attitudes and perceptions to accommodate and not lose this population. Multidisciplinary teams need to embrace the importance of ensuring that all client contacts are in the service of engagement and retention, not simply those that are special efforts of separate, designated staff for whom funding may cease to exist. Training to this end, for all levels of clinic staff, is critical.

Conclusion

In any HIV primary care clinic, a subset of patients will require more focused and specialized psychosocial services. Within this subset, Caring Connections demonstrated that there is yet another, perhaps more vulnerable, group of women that requires highly specialized attention. Women who are disengaged from the helping infrastructure as it relates to their disease are frequently identified within the system as having a “bad attitude” and being beyond reach. The program found that it takes a different approach to reach these women. For this population, reminder calls and transportation arrangements are necessary, but not sufficient, to facilitate treatment engagement. It is imperative that providers and staff see the relational opportunities
in all client contacts—specifically that all contacts be directed toward engaging and retaining clients—and that multidisciplinary teams embrace this as “business as usual” in all clinic services.
Goal of the intervention
POCAAN's Konnect II Program finds and connects HIV-positive individuals to HIV primary medical care, especially those who are newly diagnosed or never seen a HIV primary care provider. Also, the program encourages and promotes sporadic users of medical care to stay in care. This education and support is delivered both individually and in group settings.

Organizational setting and partnerships
We are a community-based organization working in partnership with the Madison Clinic at Harborview Hospital (a University of Washington hospital) and several other clinics. We also work with the health department. Konnect II is funded through a Ryan White grant for which Public Health Seattle & King County is the grantee.

Target client population
African-American and Latinos, over 18 years of age, who are below 200% of the federal poverty level and who are newly diagnosed (they have been diagnosed within the previous 24 months), are not in care or at risk of falling out of care, or are in need of culturally relevant support.

Services provided/
intervention type
We connect our clients to case management at the appropriate agencies and to outreach services through presentations in the community, at clinics, as well as in conjunction with POCAAN's own Health On Wheels (mobile) testing and counseling unit.

Staff requirements
Staff involved in the intervention included client advocates who were also peers, a mental health specialist, and a chemical dependency counselor.
Local evaluation markers

The following markers for program evaluation are used:

<table>
<thead>
<tr>
<th>Service unit name</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>New clients enrolled</td>
<td>40</td>
</tr>
<tr>
<td>Placements in care services</td>
<td>40</td>
</tr>
<tr>
<td>Face-to-face encounters</td>
<td>6,800</td>
</tr>
<tr>
<td>Telephone encounters</td>
<td>2,550</td>
</tr>
<tr>
<td>Collateral encounters</td>
<td>1,700</td>
</tr>
<tr>
<td>Discussion (support) groups</td>
<td>72 groups for 40 unduplicated clients</td>
</tr>
<tr>
<td>Educational groups</td>
<td>24 groups for 40 unduplicated clients</td>
</tr>
</tbody>
</table>

These numbers are tracked so that, among other things, we can identify the high-, medium-, and low-need clients. Any client seen or spoken to more than three times in one week during a calendar quarter is considered a high-need client.

Local evaluation results to date

Between baseline and post 12-month intervention:

- Increased number of people taking HIV medications from 68% to 79%
- Increased referrals to mental health care
People of Color Against AIDS Network (POCAAN) is a multicultural AIDS service organization located in Seattle, Washington, serving people of color infected or affected by HIV/AIDS since 1988. POCAAN is the oldest organization in Seattle serving people of color at risk for or living with HIV. POCAAN’s mission is to bring together people of color across differences in race, gender, class, and sexual orientation and remove barriers created by sexism, racism, and homophobia that limit the ability to access health care services and educational risk-reduction messages about HIV/AIDS. Creating client-centered services to meet the needs of underserved people living with HIV/AIDS requires human and financial resources that one organization may not be able to meet. In Seattle, Washington, one organization tried to overcome this challenge by building community partnerships with other AIDS service organizations in its region.

In 2000 POCAAN created the Konnect II Client Advocacy Program as part of the Minority AIDS Initiative. The goal of the the Konnect II Program is to reach out to HIV-infected, low-income, Latino and African-American populations who are not in care, are at risk of falling out of care (missing medical appointments), or are newly diagnosed (within two years) with the disease in order to engage and retain them in HIV medical care. This program was initiated to help Latinos and African-Americans in the Seattle area enter care at an earlier point in the disease and stay healthy for a longer period of time. Konnect II employs people from the affected target communities as client advocates or peer supporters to help identify HIV-infected clients and connect them with services, care, and support in their community.

**Challenge: Developing partnerships to deliver culturally appropriate care**

The Konnect II niche is to provide culturally appropriate information, services, and support to people living with HIV/AIDS. Konnect II provides client advocacy, emotional support, educational and support groups, peer support, alcohol/chemical dependency counseling, accompaniment to initial medical appointments, treatment support, mental health assessments, evaluation, and counseling. Our clients are referred to the appropriate providers for medical care, case management, housing, or other service needs that are often essential to people living with HIV. Therefore to implement the intervention and ensure that people are connected to medical care and case management, Konnect II needed to create a network with community partners and develop a formal process for referrals between agencies. In addition, to document the impact of the Konnect II intervention on engagement and retention in HIV primary care, Konnect II needed to track client receipt of medical care and treatment, including CD4 and viral load tests, on a quarterly basis. This tracking function also required a strong collaboration with other community partners.
Developing Memoranda of Agreement with partners and renewing them each year

Konnect II identified key agencies within the continuum of HIV care in the Seattle area and hosted meetings with each to promote a shared understanding of what agency could do and how they could work together to promote engagement and retention in HIV services within communities of color. These agencies included:

- **Seattle Treatment Education Project** — a project that provides education and speakers for educational seminars. The purpose of this relationship is to coordinate treatment information and advocacy for the clients and staff involved in the Konnect II program.

- **Multifaith Works** — a nonprofit, non-denominational organization that provides housing and supportive services to people living with AIDS or other life-threatening illnesses, and provides community education on issues of human diversity. The purpose of this relationship is twofold: Multifaith can and does provide housing for our clients, and they refer persons living with HIV/AIDS to services available at Konnect II.

- **Lifelong AIDS Alliance** — an organization that provides HIV prevention education, case management, housing, insurance, transportation, nutrition services, and other practical support services for those whose lives are affected by HIV, including Konnect II clients. The AIDS/HIV Care Access Project (ACAP), a part of Lifelong, also schedules primary care and dental appointments for newly diagnosed individuals, including some of the Konnect II clients.

- **Consejo Counseling and Referral Services** — an organization that provides HIV prevention education, treatment education, and support services related to mental health, substance abuse, and domestic violence, mainly targeted to the Hispanic/Latino community. Consejo provides case management services for clients referred by Konnect II/POCAAN.

- **Gay City Health Project** — an organization that provides HIV/STD testing and screening to a broad client base in addition to providing HIV prevention programs that serve gay and bisexual men. The purpose of this relationship is to coordinate a systematic referral system from Gay City’s HIV Testing and Counseling to the Konnect II Client Advocacy Program/POCAAN upon post-counseling.

- **University of Washington Medical Center Roosevelt Virology Clinic** — provides primary care services to HIV-positive clients referred by POCAAN/Konnect II. The purpose of this relationship was to generate referrals, ensure access to medical care, and track client utilization of services and clinical outcomes.

- **The Madison Clinic at Harborview Hospital, a University of Washington hospital** — provides most of the HIV/AIDS primary care and case management in the
Making the Connection

The purpose of this relationship was to ensure access to medical care, generate referrals, and track client utilization of services and clinical outcomes.

We developed a Memorandum of Agreement (MOA) format that was reviewed by each agency and tailored to address their individual needs. The Executive Directors of both agencies signed the documents. These Memoranda of Agreement are renewed as needed between Konnect II and each of the other agencies. A sample MOA is in Appendix 6 (see POCAAN MOA).

**Going beyond the Memoranda of Agreement: Linking clients to culturally appropriate care**

While the MOAs helped to establish the network, and individual meetings with each agency reinforced the network, receiving referrals from partners for culturally supportive care remained a challenge. We needed to advocate for our services in a broader fashion. Staff from the County Health Department sent letters to our partner agencies reminding them of their responsibilities to the program. This improved the flow of data for reporting purposes, but not necessarily the flow of referrals. The epidemiology of HIV in the Seattle area is such that Latinos and African-Americans constitute a relatively small portion of the HIV/AIDS caseload in the community, as compared with other parts of the country. Konnect II’s role as care facilitator and advocate for African-Americans and Latinos in a largely white provider community means that we help people understand that they have choices, and help them access care in a way that works for them. For example, if a Spanish-speaking client wants to receive case management services from a case manager who speaks his language, Konnect II will help him access this care, even if it means that he has to change his clinic affiliation because the case manager is connected with another primary care provider. Similarly, if a client is not going back for regularly scheduled visits because of a negative experience with a provider, Konnect II will try to work with that provider to clear up misunderstandings or improve communications. If it is clear that this effort is not working, Konnect II will help the client find a new provider who will better meet his needs.

This type of advocacy is challenging and sensitive, and it is not surprising that some partners were cautious about referring their clients to the Konnect II program. Since Konnect II was initiated from the Congressional Black Caucus Minority AIDS Initiative (MAI) the program is required to

POCAAN staff

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engage clients so they may have early access to, retention in, and culturally appropriate care to sustain healthy lives. Referrals to the Konnect II program increased when one of the Konnect II collaborating agencies received MAI funds and employed a former POCAAN employee who had a better understanding of the importance of advocacy functions as well as long-standing relationships with Konnect II staff.

Conducting mental health and chemical dependency interventions

Early on, Konnect II—through collaboration with the Washington State Department of Health—had access to a chemical dependency professional. This was helpful in referring clients to appropriate treatment as needed. Although health department funding for this was later lost, thanks to collaboration with the HRSA/SPNS Outreach Initiative, the program was able to hire a chemical dependency professional to continue these referrals.

The initial mental health intervention consists of screenings and then, if needed, referrals into care. The program hired a mental health therapist who does evaluations, treatment plans, and therapy. Many clients, including a number of our Latino clients, have completed the screenings and see the need for mental health intervention.

Hosting workshops and events to maintain partnerships

Konnect II hosted a diversity workshop for our collaborating service providers in Seattle/King County. The workshop was designed to help providers become more knowledgeable and aware of the cultural issues related to care-seeking experiences and behavior in communities of color, and to improve their cultural competency and make their services more accessible. To increase the participation and commitment of our partners in the workshops, Konnect II sent questionnaires to the agencies requesting their input on how to develop this workshop and what topics should be discussed. Konnect II also hosted community social events for clients and partner agencies to promote networking and service relationships and to share important updates in HIV prevention, care, and treatment.

Conclusion

Konnect II’s success in building community partnerships has helped to improve HIV care and treatment services across the Seattle/King County region in many ways. The partnerships have helped make HIV services more client-centered and culturally appropriate. Community partnerships have created a network of services for clients who can choose the service that meet their needs. In addition, partner agencies have been able to adapt their services and make them more culturally relevant for clients. Finally, POCAAN as an agency extended its care network and knowledge of services, and is better able to advocate for clients by effectively referring them to partners who best fit their needs.
Engaging in community participatory research to evaluate an intervention to engage and retain people in HIV care

Drew University Mobile Health Outreach Project/UCLA Los Angeles, CA

**Goal of the intervention**
To identify previously undiagnosed HIV-positive individuals and then get these individuals connected to HIV-related primary medical care, and to link HIV-positive individuals with a full spectrum of HIV and other health and social-related services through case management.

**Organizational setting and partnerships**
Our study is based on a collaborative partnership between the UCLA School of Medicine and the Drew University Mobile Health Outreach Project. The Drew University Mobile Health Outreach Project has provided outreach and HIV counseling, testing, and referral services to at-risk populations in Los Angeles County since 1992.

**Target client population**
Commercial sex workers, runaway youth, the homeless, undocumented workers, gang members, teen parents, women of childbearing age, adult and adolescent MSMS of color, and transgender/transsexual persons of color in the South Central, Hollywood, West Hollywood, East LA, and downtown neighborhoods of Los Angeles.

**Services provided/intervention type**
Case management services are provided to study participants in a private, one-on-one setting, individualized to meet each person’s needs. The case management program is composed of the four following components: intake, assessment, referral, and follow up.

» **Intake** is designed to review the needs of the client based on information collected at the baseline interview, and provides the first opportunity to inform the client of the full spectrum of services available, including case management for persons testing HIV-positive.

» **Assessment** is the synthesis of information describing the client’s physical, psychological, and social status. From the completed assessment a care plan is devised by the case manager, which includes referrals to other needed service providers and plans for follow up.

» The **referral** process consists of the development of short-term and long-term objectives for maximizing engagement and retention in care.

» The case managers **follow up** with clients through a variety of means to ensure that they received services and that
their needs are met so that patients are retained in care.

**Staff requirements**

One full time case manager (bilingual English/Spanish; five interviewers (two bilingual English/Spanish); medical record abstractor; research and evaluation team (Principal Investigator, Co-Investigator, Project Director). The Principal Investigator and Co-Investigator oversee all aspects of the program design, implementation, and evaluation. The Project Director oversees data entry, medical record abstractions, and IRB submissions.

**Local evaluation markers**

- **Engagement in care**—amount of time it takes for individuals to get initial HIV care from the time that they tested positive
- **Retention in HIV-related care**—longest time period without HIV care, a regular source of HIV care, a regular HIV care provider, number of times a HIV care provider was seen in the past six months, number of missed appointments in the past six months
- **Barriers to care and unmet needs**—discrimination, stigma, health beliefs, structural and financial barriers, self-reported access to care, whether the client has a case manager, whether the client received as much case management as needed, life chaos

**Health outcomes**—adherence to medications, use of antiretroviral therapy, hospital and emergency department visits, health status, CD4 count and viral load.

**Local evaluation results**

Results between baseline and post 6-month intervention:

- Reduction in the percentage of participants with 1 or more missed appointments from 51% to 43%*
- Increase in the percentage of participants with 2 or more medical visits in 6 months from 68% to 74%*
- Reduction in the percentage of emergency room visits from 32% to 23%*
- Increase in the percentage of participants with a case manager from 52% to 65%*
- Reduction in the percentage of participants experiencing 1 or more barriers to care from 90% to 52%*
- Improvement in mental health status as measured by SF-12 quality of life score from 42 to 45
- Increase in the percentage of participants taking HIV medications from 64% to 73%*
- Increase in the use of anti-retroviral treatment among people with CD4 < 350 (from 74% to 88%)*
- Increased percentage of participants with undetectable viral load (from 50% to 58%)*

*p <.05
In 2000 The Drew University Mobile Health Outreach Project (MoHOP) entered into partnership with UCLA’s Department of General Medicine, School of Public Health, to evaluate an HIV mobile testing and outreach project in Los Angeles County and implement an enhanced intervention to engage and retain those who tested HIV-positive in HIV primary care. The primary goal of MoHOP has been to provide free HIV screening, counseling, and referral services to at-risk populations residing in South Central Los Angeles, Hollywood, West Hollywood, East Los Angeles, and Downtown Los Angeles (Skid Row). However, because the project did not have anyone designated to follow up with HIV-positive clients after the delivery of test results and referral to care, it was not known how many HIV-positive clients actually entered into care after testing positive on the MoHOP outreach van.

By collaborating with UCLA, which has expertise and resources to assist in the design and implementation of the program evaluation, MoHOP was able to engage in community participatory research. The purpose of this research was first to determine the effectiveness of the mobile HIV testing and outreach program in connecting newly diagnosed HIV-positive individuals with care and treatment, and second to evaluate an intervention to improve engagement and retention in HIV care over time. This enhanced intervention model was developed after convening client focus groups that identified unmet needs, gaps in services, and barriers to care. The model added a full-time bilingual case manager to the mobile van team.

Challenge: Trying to find the people who tested positive at the mobile van
The program first had to identify as many individuals as possible who tested HIV-positive at the MoHOP mobile van between 1992 and 2000, locate them to find out if the referrals to care resulted in access to medical care, and determine whether or not the client received ongoing HIV/AIDS-related care and treatment over time. For clients who tested confidentially and for whom the project had locating information, we set out to find and recruit these clients into the study. For HIV-positive clients who tested anonymously and for clients whose contact information was out of date, the community-based clinics who received the initial referrals were contacted in order to solicit their support and participation in locating these HIV-positive clients. Because of excellent working relationships with these community-based organizations over the past 14 years, the program was able to recruit many individuals into the study by collaborating with staff at these agencies and through word
of mouth. The program was also able to recruit subjects into the study by distributing or posting recruitment flyers at local HIV clinics, HIV housing programs, and community-based organizations (CBOs) that provide HIV-related case management, transportation, benefits counseling, and psychosocial support.

No incentives were provided to local CBOs or HIV clinics to enlist their support for this study, except when we had to obtain Institutional Review Board (IRB) approval for recruitment of study participants or when a large number of study participants were being followed. In these cases a small stipend was allocated to the respective agency or individual working with the program to obtain IRB approval or approval from clinic administrators for the research team members to conduct on site recruitment over an extended period of time.

**Obtaining Institutional Review Board approvals from public and private sector organizations**

Because of the large prospective client base from which to recruit potential clients into the study, relationships with community-based and university-based Institutional Review Boards had to be developed in order to obtain approval to implement the intervention and the study. For example, the program engaged in a process taking several months in order to obtain IRB approval to recruit clients enrolled at a local HIV/AIDS treatment clinic housed on the campus of the Los Angeles County/USC Medical Center, and it was also a lengthy process to obtain IRB approval to recruit clients at Harbor/UCLA Medical Center. The program also had to obtain approval from the IRB committees of UCLA’s School of Public Health and Charles R. Drew University, the institutions partnering to implement the intervention and the study. Finally, IRB approval had to be obtained from our local partner organization, Shields for Families, from whom participants were recruited. In one case, some of our grant funds were allocated to pay an IRB to process the paperwork to review the IRB application. Thus, to implement the enhanced intervention and evaluate its effectiveness, the program had to obtain IRB approval from five different community-based or university-affiliated organizations.

**Delegating work responsibilities to research team members**

Early in the planning process, consensus was developed around the specific duties and responsibilities assigned to each team member working on the project so that the MoHOP project staff who were representative of the community being served had specific expertise and work responsibilities, and the staff from UCLA had specific expertise and work responsibilities. MoHOP staff was trained to conduct client recruitment, client interviews, case management and follow up, and other programmatic activities within the demonstration. UCLA staff was assigned to work with IRBs, develop surveys, conduct medical record chart reviews, and oversee data management and analysis. Because obtaining IRB approval can be a very lengthy and tedious endeavor, it was necessary to designate one member of the research team whose sole responsibility was to ensure all appropriate IRB paperwork got forwarded to IRB committees when requested and respond to all requests for additional information or changes in the research protocol recommended by the respective IRBs. This person stayed in constant communication with staff from each IRB to address questions or concerns.
by committee members. This person also ensured that we responded to all of the required IRB renewal dates and were in constant compliance with all IRB requirements so that there would be no interruptions in the implementation of the project.

**Establishing relationships with partner community-based organizations for research and care**
The research involved extensive recruitment and retention of clients from several public and private sector community-based or university-based clinics and social service agencies, including AIDS Healthcare Foundation, Bienestar, Harbor/UCLA Medical Center, Drew University’s Early Intervention Treatment Clinic, the OASIS Clinic, the Spectrum program, and other community-based projects. MoHOP and UCLA team members built upon existing relationships with administrative staff and line staff at these respective agencies in order to gain their trust, support, and active participation in the research study.

All of the aforementioned agencies provide HIV/AIDS treatment, support, or case management services to HIV-positive clients.

The program’s services merely enhance what these agencies are already doing, but without duplicating services. For example, if a client does not qualify for case management services at a particular agency, agency staff can refer the client to the demonstration program and the client can receive services from our case manager. With some partners, the program negotiated nominal consulting fees for staff to work with the project research team extensively throughout all aspects of the research study’s coordination, implementation, and evaluation processes.

Some community partners made requests to establish Memoranda of Understanding (MOUs) with both UCLA and Drew University. By establishing MOUs with specific organizations, the program was able to clearly delineate the roles and responsibilities of each participating agency and/or collaborative partner, and delineate the desired process and outcome objectives with the full cooperation and active participation of our community partners. A sample MOU is in Appendix 7 (see MoHOP/Bienestar MOU).

**Providing staff training on the research protocol and the intervention**
The program provided staff training to the MoHOP and UCLA staff on all aspects of the project. Topics included participant recruitment and eligibility, tracking participant status in the program at six months and/or 12 months, withdrawals, and potential public and/or private sector funding available to sustain the project. We also developed a case management protocol and training manual for our intervention.

During the project start-up phase, the program had monthly meetings with five...
community collaborators in order to successfully recruit sufficient numbers of HIV-positive clients who had tested positive at the mobile van counseling and testing program. The program obtained IRB approvals from all of these programs and provided quarterly updates with their staff on the progress of the study. Program staff also attended monthly meetings of the administrative staff at the clinic where the majority of clients were recruited in order to provide program status reports, answer questions from staff, and address issues which had come up regarding recruitment and chart review efforts. As the program evolved, program staff discontinued monthly meetings with other organizations, but did continue to provide periodic program updates.

Conclusions

In conducting community participatory research, a program cannot avoid obtaining IRB approval, often from multiple organizations. Thus, a program should plan enough time and staff resources into its methodology and budget to obtain IRB approval in order to complete the study without delays due to the IRB approval process. It is important to establish relationships with IRB staff so that they get to know program staff and are willing to explain and expedite the IRB process.

It is also important to establish a “level playing field” between university researchers and community-based service providers early on program development. Each partner has important skills and knowledge to contribute to the research study. The community-based providers need to let everyone know up front that they have just as important a role to play in achieving the overall success of the project as everyone else at the table. The community-based providers should be held in the same esteem as the academics, and must be listened to and respected as much as anyone else involved in the research study.

One of the major challenges is the sustainability of the program’s intervention. The data results demonstrate an “enhanced case management” model does improve the overall health and well-being of clients who are medically underserved. It is important to share these findings with other community-based providers, academicians, and public policy makers so that agencies will not have to reinvent the wheel.

Community participatory research can only be successful when relationships are developed and/or enhanced based upon mutual trust and respect by the public and private sector entities working together for the common good of the community to be served. Obtaining IRB approval, gaining the trust and respect of collaborators, communicating on an ongoing basis with your partners, instituting an extensive staff training so that everyone knows their roles and job responsibilities, obtaining feedback from clients to be able to address the priority issues impacting their lives, and developing MOUs that clearly delineate the roles and responsibilities of all entities working in partnership to coordinate, implement, and evaluate the proposed community-based research—these are all essential elements in the process of developing, implementing, and evaluating successful community participatory research projects.
Staying on track: Management systems to track staff efforts in keeping hard-to-reach people living with HIV and AIDS in care

Project Bridge, The Miriam Hospital, Providence, RI

Goal of the intervention
Project Bridge is focused on retaining HIV-positive individuals in care by promoting the regular use of HIV care for individuals who were connected to care while incarcerated. Project Bridge provides outreach and intensive case management for 18 months to ensure that they are retained in care.

Organizational setting and partnerships
Project Bridge is community-based but also connected to an Infectious Disease clinic at a hospital. The program is urban but also serves individuals throughout the state. Our primary partners are the state Corrections Department and the Infectious Disease clinic at the hospital. However, we also work actively with a broad range of other agencies, such as local AIDS service organizations, housing providers, and mental health and substance abuse treatment providers to ensure that clients obtain the full range of services to support their stability.

Target client population
Project Bridge targets both men and women ages 18 and over who are being released from any of the state’s correctional facilities.

Services provided/intervention type
The Phase II Project Bridge intervention includes team-based intensive case management for 18 months. The intensive case management component includes assisting with referrals to all services, accompanying clients to all medical appointments and many other appointments, providing treatment planning and counseling, and offering other support to assist clients ensure their retention in care and enhance their overall community stability. A Skill-Building/Health Literacy Group and other types of support groups are also offered.
Staff requirements
Each client has a case management team that includes a social worker and an outreach worker. Therefore, all social workers are required to have Masters degrees in social work (M.S.W.). Although not mandatory, it is strongly preferred that the outreach workers have Bachelors degrees in social work (B.S.W.). Social workers develop the treatment plan and manage the medical, mental health, and substance abuse services; outreach workers manage the support services.

Local evaluation markers
The primary indicator used to measure the effectiveness of Project Bridge at the local level is overall retention in care, as measured by number of HIV medical visits and number of missed medical appointments. Other key indicators include increased community stability as measured by receipt of benefits, housing, or increases in income; retention and engagement in Project Bridge; changes in health literacy; and client satisfaction with Project Bridge.

Local evaluation results
Between baseline and post 12-month intervention:

- 83% of participants were retained in care (2 medical visits in the past 6 months)
- Reduction in the percentage of participants with missed appointments from 27% to 23%
- Increase in the percentage of participants taking HIV medications from 47% to 71%
- Increase in the percentage of participants with undetectable load from 47% to 61%
- Increase in measures of community stability:
  - Increase in the percentage of participants with health insurance from 45% to 83%
  - Increase in the percentage of participants with own housing from 11% to 27%
  - Reduction in the percentage of participants with unmet needs from 82% to 52%

- Improved health literacy:
  - Increase in the percentage of participants discussing a treatment plan with their health care provider from 60% to 87%
  - Increase in the percentage of participants discussing lab tests with their health care provider from 60% to 71%

* p <.05  
** Between 6 and 12 months post-intervention
Project Bridge is a program of The Miriam Hospital that is located in the minority community. It provides outreach and case management services for HIV-positive ex-offenders. Project Bridge’s mission is to retain HIV-positive ex-offenders in medical care through social stabilization. Social stability is achieved by assisting clients to meet their basic survival needs (food, clothing, transportation, and shelter), their health care needs (medical appointments, obtaining medications, health insurance, and ancillary care) and their longer term needs (readiness for mental health and substance abuse treatment, payment of fines, attending meetings with parole officers, addressing outstanding warrants, reestablishing connections with family, education/employment, and developing a social network). Our clients do not arrive at a destination called “social stability.” It is an ongoing process of teaching by example, by coaching, rehearsing, and reviewing techniques for accessing resources and maintaining those resources. Each client at Project Bridge works with a case management team that consists of a masters level social worker and a non-peer outreach worker. The social workers develop treatment plans and manage the medical, mental health, and substance abuse services while the outreach workers manage support services. The program’s services are community-based, which means that encounters occur in the client’s environment, not in an office or clinic.

**Challenge: Addressing the needs of clients with multiple barriers to care in a fragmented service system**

There are three main challenges in providing services to ex-offenders: individual issues, barriers to benefits, and systems-level barriers. Nearly all Project Bridge clients have a history of substance use and a majority of them have mental health needs. Many are disconnected from their families and social networks due to repeated incarcerations and addiction. They have few coping mechanisms and a low tolerance for stress. Over 60% have never been employed and few have marketable skills. These are just a few of the individual issues that Project Bridge clients face. Second, depending on state regulations and the particular offense, clients may not be eligible for certain services or benefits such as public housing and food stamps. Finally, the various “systems” of care—such as mental health, substance abuse, and social services—are unresponsive and uncoordinated. Services are provided through a middle-class model of appointments, insurance, and documentation requirements that create unmanageable hurdles for our clients. Most clients accept a denial of service as final, and it is our role to assist them in advocating for a fair hearing and in presenting the particulars of their case in order to have the decision reversed. Regardless of outcome, it teaches clients to be respectfully assertive.

**Working with other providers**

To address these challenges Project Bridge has developed management systems to stay abreast of client needs and service outcomes. Local social service organizations

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**Establishing written linkage agreements is a first step in coordinating care; however, it is not a substitute for knowing direct care staff.**

Establishing written linkage agreements is a first step in coordinating care; however, it is not a substitute for knowing direct care staff. It is an ongoing process of teaching by example, by coaching, rehearsing, and reviewing techniques for accessing resources and maintaining those resources. Each client at Project Bridge works with a case management team that consists of a masters level social worker and a non-peer outreach worker. The social workers develop treatment plans and manage the medical, mental health, and substance abuse services while the outreach workers manage support services. The program’s services are community-based, which means that encounters occur in the client’s environment, not in an office or clinic.
and state agencies provide the ancillary services for clients; therefore, the staff needs good working relationships with these providers. Establishing written linkage agreements is a first step in coordinating care; however, it is not a substitute for knowing direct care staff. As part of the employee orientation process, all newly hired staff members meet their peers in the agencies that they work with the most intensively.

The program staff members frequently convene case conferences with other providers—housing, mental health, health care, substance abuse treatment—usually around a particular issue facing a client, but sometimes to address multiple issues. These conferences clarify roles and expectations for all providers, prevent duplication of services, and assure that everyone is working on the same goals. Clients attend these conferences because it demonstrates respect for their autonomy and encourages their contribution, which is necessary to develop an agreed-on plan of action that they are able to implement. Client participation also prevents any tendency toward hidden agendas, blaming the victim, and manipulation. Finally, case conferences improve provider accountability because all activities and decisions are documented on case conference forms that record who attended, steps identified, and responsible parties.

**Developing accountability: Referral tracking, client tracking, staff productivity and effectiveness**

One important lesson learned over the years is that clients become lost to follow-up when tracking systems are weak. If staff members are not aware when a client disappears, they do not start looking for them until he or she is long gone. If it is noticed that someone is missing more quickly, efforts to find them can begin right away—checking with friends and family (when permitted), hospitals, corrections, and other providers—and they are more likely to be brought back into care. Thus, the system of program documentation and supervision focuses on client-level tracking. Staff members review the entire caseload and pending cases during weekly staff meetings. Each day is started with a short meeting to discuss daily schedules and identify people who have recently missed an appointment or with whom we have had no contact for a month without a known reason. The assigned worker makes telephone calls, home visits, calls the clinic to check for hospitalization or walk-in appointments, checks for arrests, and contacts other

Our tracking system consists of the following:

- Client level tracking of those who missed appointments or with whom we had no contact for one month
- Referrals to other service providers including the date, type, agency, and outcomes
- Client progress in treatment goals
- Staff/client encounters
involved providers. The process continues until the client is located. Clients who have been reincarcerated receive a visit by their case manager within 10 working days. This is very effective at reconnecting with people who may have been difficult to locate. Persistence, coupled with an expectation that clients will be found, consistently results in reengaging the client.

The program’s documentation system also includes tracking on a single log all referrals by date, type of service, agency and outcome, staff contacts with clients, collaterals, and clinic appointments. Client progress on treatment goals is tracked by updating a field on the treatment plan, progress notes, and by semiannual summary forms. These systems are useful for several purposes. Referral tracking helps staff to keep abreast of a client’s progress in meeting their basic survival and service needs. An Access database is used to track referrals. The staff/client encounter information and referral outcomes supply data for advocacy. The encounter information helps to document frequency, length of contacts, and efforts to locate missing clients. It also helps indicate which clients require the most time and why in order to better manage and assign caseloads. (The program’s caseloads are small because our clients have such intense service needs.) Finally, when staff are community-based, it is important that they document what they are doing and that they know their managers will be looking at this information. Staff account for the length of time and the types and frequency of contacts they have with or on behalf of clients. Logs are a simple way of reporting this activity. Samples of our referral and case management logs are in appendices 8 and 9.

In the program’s management system, one person is responsible for data entry into the system, filing, and record security. It was found that if many people were responsible the job was not done accurately; consistency of approach yields consistency of results. Specific dates were established for staff to submit their logs, and a written standard for the timeliness of documentation is communicated to staff and linked to annual performance reviews. The program also maintains written standards for the frequency of client contact, caseload size, and the percentage of time spent on direct service. Administrative tasks, holidays, and absences are deducted from the total hours each month to calculate staff productivity, and these results are shared on a monthly basis with individual staff members. Resulting caseload adjustments are data driven.

The clinical effectiveness of staff work is evaluated through a review of intake assessments, treatment plans, progress notes, closing summaries, and referrals. A clinical supervisor reviews these documents for both appropriateness and completeness. The timeliness of staff work can be assessed using a document checklist at the front of a client’s record. The checklist includes important target dates and completion dates, including client intake date and agreement to enter into the program, baseline treatment plan, completion dates for updated plans at six-month intervals, dates
of semiannual summary submissions, and closing dates. The date of application for ADAP (AIDS Drug Assistance Program), date of HIPAA notification, and dates of case conferences are also on the form. These are reviewed through a quality management process and the results shared with the staff members in individual supervision.

Conclusions
While the Project Bridge model is intensive, it is effective. It has been noted by researchers that the health benefits offenders obtain from antiretroviral treatment regimens in correctional facilities are quickly lost following community re-entry. Project Bridge has prevented this by retaining over 95% of its participants in medical care during the program and has a completion rate of 77% for an 18-month enrollment. Only 9% of our clients are closed as being lost to follow-up. Chart reviews show that 93% of former clients continue to receive medical care six months after they completed the program. This is accomplished by combining a harm reduction philosophy with active outreach to clients who miss appointments. Clients find a welcome regardless of circumstances. Furthermore, because the program’s clients are multiply diagnosed, they do not fare well when given the standard level of care offered by other community programs. They require an active, long-term, consistent approach.

The program provides consistency and persistence in its pursuit of mutually agreed-upon goals. While the use of a team is unusual and may seem an unnecessary expense, the benefits to the client are apparent in terms of (1) someone always being available to assist them, and (2) the level of advocacy and health communication support they receive. Several years ago, we determined the cost for eighteen months of service to a client. The cost for a client without a major mental disorder, adjusted for inflation, is approximately $6,490 and for those with a major mental disorder it is approximately $9,440. Compared to the cost—both in absolute dollars and in social/public health terms—of medical care for a sporadic/disengaged user of health care, the cost of untreated mental illness, or the cost of incarceration—which hovers at approximately $150 per day—we believe that it is money well spent.

Notes

The sites funded under the HRSA/SPNS Outreach Initiative received additional funding to conduct extensive local and multi-site research and evaluation to measure the effectiveness of their program interventions in engaging and retaining people in HIV medical care. Given that the ability to demonstrate the effectiveness of these types of programs is essential to sustainability, it is important to consider mechanisms for conducting program evaluation. However, in the absence of special evaluation funding, we recognize that developing practical tools for measuring program effectiveness can be daunting, especially for smaller agencies. Regardless of participation in research, it is essential that evaluation be an integral part of any program’s work plan. First, it is important to be able to demonstrate that programs providing services to find PLWHA who are out-of-care or at risk of falling out of care and helping to engage or retain them in HIV primary care are effective in their role, especially for funding agencies. Second, program evaluation helps identify ways to improve the quality of services to better serve people living with HIV/AIDS in our community.

Selecting measures of program effectiveness

The first step in program evaluation is defining clearly the measures for effectiveness. As a non-medical site and a program originally funded by Title I of the Ryan White CARE Act, Cascade AIDS Project (CAP) needed to develop and define some criteria for understanding a person’s engagement in medical care. So, regardless of the criteria, it is important to define them up front so that there is something on which to base clients’ progress in the engagement and retention process.

Before CAP began providing Title I services, five program criteria were developed. If program clients met four out of the five criteria they were considered to be “engaged in medical care.” These criteria became the outcome measures for our contract, and were used to establish client goals. They also provided a way to measure success in getting people into care (engagement) or keeping them from falling out of care (retention). The program focused on measurements that were relatively easy to collect either via client self-report or from other providers with whom we had established relationships. By establishing clear criteria, the program could be certain to directly demonstrate measurable effects.

These criteria were developed by CAP program staff along with the local Title I grantee. During the program development and implementation process, it was realized that in addition to determining a client’s “care status” at baseline, a way was needed to determine when a client was considered to be “in care.” It was further determined that simply attending a medical appointment did not qualify someone who had not been in care for six months or longer to then be “in care” and no longer in need of outreach and advocacy services. Given the complexities of HIV and the support...
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and knowledge needed to adhere to care, a multi-factor assessment was developed. Criteria may vary from program to program, but the following criteria are used to define engagement in medical care:

1. Regularly attending medical appointments. “Regular appointments” are defined as compliance with a medical provider’s treatment plan without missing two or more appointments in a three-month period. This timeframe for missed appointments was chosen because many clients experience several complex health issues and require frequent medical attention. Receipt of medical care once every six months was not sufficient to keep them connected to care.

2. Regularly attending case management appointments. In the CareLink program, case managers used an “acuity score” based on the level of client needs in order to determine how often a person needs to be seen. Program staff worked closely with the case manager for each client to ensure that the client attended appointments as prescribed.

3. Having medical insurance (or a way to pay for care)

4. Having had a CD4 and viral load in the past three to six months (based on medical need)

5. Knowledge of what CD4 and viral load mean

Collecting the data

The information was collected at baseline using the form in Appendix 10 (see CareLink in care form). We continued to collect the information every three months until the participant qualified as “in care” for six months. The information collected on the paper form was entered electronically into our client database. There are fields for the date and the five criteria. When four out of the five criteria are met, an engagement field is automatically checked. This enables tracking the progress of engagement over time by running corresponding queries.

It is important to note that information is NOT based on client report, other than at baseline. If the client is loosely connected to services and has been referred by their case manager, CareLink staff verify the information at baseline. For clients who are out of care at baseline and do not have a previous connection to services from which to gather that information, their self-report data at baseline is used. To track their program status over time, the program staff conduct regular assessments via the medical site or case management agency.

Using the data for program services

Data collected are used to assess how successful the program is in moving people into care and case management services. Because the program is short-term and intensive,
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staff are then able to “graduate” people after six months of meeting the criteria for being “in care.” Client program status is tracked with the following categories:

- Active: In Process
- Active: Engaged
- Inactive: Graduated
- Inactive: Moved/Transitioned
- Inactive: Moved/Lost
- Inactive: Lost or Dropped Out
- Inactive: Deceased

On a biannual basis, categories are reviewed to make sure they are up to date based on care engagement criteria. This gives staff an opportunity to discuss those clients who have not experienced success engaging in care and brainstorm new strategies to move them along in this process. Now that the program is in its fifth year, this process has provided a mechanism for determining which clients may experience long-term challenges and how the program can successfully engage them in care within the context of our local HIV service continuum.

Developing systems for measuring program effectiveness can be done many ways. This is just one way that was developed within the environmental context of Portland’s local HIV care continuum to monitor the program’s success over time without using medical outcomes.

The program focused on measurements that were relatively easy to collect either via client self-report or from other providers with whom we had established relationships. By establishing clear criteria, the program could be certain to directly demonstrate measurable effects.
“What do you do to bring people who are not in medical care into care and treatment?” We asked this question of staff members from seven programs of the HRSA/SPNS Outreach Initiative. The program staff included 21 men and women; approximately half were African-Americans and Latinos. Nine identified themselves as peers, meaning from the same ethnicity, gender, sexual orientation, or HIV status as their clients. Their professional backgrounds varied: five considered themselves clinicians—either nurses or licensed social workers—and the others had diverse titles such as advocates, case managers, outreach workers, or health systems navigators. All staff worked directly with clients to engage and retain them in care.

Staff members described clients who they considered to be “not in care” versus “in care,” and often told the story of how a person came to be “in care.” The following themes emerged regarding the role of staff in helping people to engage and remain in HIV primary care.

**Finding people**

Staff spent a significant amount of time trying to find and reconnect with people who were not in care or who sporadically used medical services. Usually staff would receive a referral from a clinic or case manager that the client was lost to follow-up or had missed appointments, and sometimes staff would know from their own relationship with a client that the person was no longer in care. Some staff went to client homes and talked with family members or neighbors about the client’s last known whereabouts. Others went to client hangouts, such as street corners or clubs, or community agencies that provided meals, clothing, and shelter. Staff worked hard to establish strong relationships with other community organizations that provided direct services or met basic needs for clothing and food to try and locate clients who were lost to follow-up.

**IRENE:** It’s always at the home. I keep searching. I keep working. I give an address, ask the neighbor do they know this person, or have they seen her. They say, no, she moved. And we backtrack and go back to the clinic and try to get a new address, and we just keep going, or I’ll leave a letter, or I’ll leave a card until I reach them unless they move out of the state or something like that.

**QUESTA:** I work with this guy every single day. He’s actually kind of homeless . . . hasn’t officially found a place to stay. He stays in a shelter, with family, or with friends . . . He usually hangs out at Dunkin’ Donuts on the corner on the street. I see him every single morning. I see him everywhere.

**Providing services and practical support**

Once clients are located by outreach program staff, the staff member assists clients with obtaining services so they become more regular users of medical care. For some staff members this included making reminder phone calls about appointments; accompanying clients to appointments for medical care or other social services; helping to obtain benefits such as medical insurance, prescription drugs or social security; making referrals; connecting clients to mental health services; and arranging trans-
portation to appointments. Staff varied in their level of involvement in providing the type of services, but all mentioned the importance of addressing the other social support needs of clients either at the same time or prior to assisting with medical needs in order to improve the likelihood of retaining clients in HIV care.

MADELINE: Some of the activities that we do . . . reminder phone calls, accompany clients to medical appointments, and making sure they know what it is they need to follow through on, whatever doctor directions they get, go to the pharmacy. If they need help with benefits or entitlements, we either refer them—which is another big part of what we do, referring to case management, referring to mental health services, addiction services, just anything that comes up along the way. And, then, basically, just helping them solve problems within the clinic.

Staff improved clients’ knowledge about the HIV service system in their community and described how they helped clients access services and manage their relationship with different providers. A key activity was helping clients improve communication with their doctors and other service providers. Some staff served as mediators with other providers or worked with clients to practice skills in asking questions of providers in order to address their own needs.

WENDY: I think that helping him . . . establish that stability among the network of providers here [helped him]. I was the first one who had contact with him and then worked to get him into case management, worked to get him into [a program for dual diagnosis] and helped him establish that network of stability. And he always knew he could show up here as well, so that . . . was his first kind of connection . . . I was kind of the glue at the beginning to help put the service provider system together.

CLIFFORD: He was scared. There’s a lack of communication between him and his past providers. He never really found one that he connected with and answered his questions and that . . . explained things to him so that he could understand it . . . but if someone could . . . whenever he goes in to a doctor’s appointment, just sit down and talk through what actually happens during those sessions, writing down questions, making sure that he goes in knowing this is what is supposed to happen. These are the questions I have. And making sure that all of his questions are answered.

Building relationships
Relationship-building with clients was a primary activity for staff in helping to engage and retain people in HIV care. In describing their process, staff members described
two components of relationship-building: their attitude toward working with clients, and their action steps depending on the client’s readiness to change their health care–seeking behaviors.

Having a nonjudgmental, patient, and sensitive approach
Staff described the importance of maintaining a nonjudgmental and patient attitude. Showing clients that they will not be punished for missing appointments or for drug use, accepting them for where they are, and not forcing them to take steps before they are ready all played a role in helping staff work successfully with clients.

FIONA: So we got this here user that’s on crack that’s HIV positive that doesn’t have medical care, and with time and consistency and persistence, this no medical care user eventually turns out to be a medical care user . . . and turns out to be not a [drug] user. You know it depends on where they’re at and what they actually want and what . . . trigger are we going to have to make them realize that this is what I need. So, I might deal with you one way; . . . and I might deal with [another person] in another way because she’s a different person. You know what’s good for you doesn’t have to be good for her.

JASPER: Yes. You asked me what do I think I can do about this to help this person and pretty much I would have to just go at their own pace. I could just encourage them of the benefits of coming into medical care and how it would help them, but not force them to do it because that is only going to push them away even more. So I try to just be caring and just reflect on how they are feeling as far as what they tell me, and then just go at their own pace because eventually they will come. You just have to make them feel a lot more comfortable.

Promoting self-acceptance and skills to manage HIV
Helping a client to recognize that they can live a positive, healthy life with HIV is an important step for many people. Several staff members described techniques they used with clients who were not in care to help them cope with HIV. These techniques including working individually or in groups to identify ways to avoid negative and promote positive behaviors, and to help clients decide if and how to disclose their HIV status to family and friends.

JASPER: I always affirm them. I say, “That is great. You have been using all of your strengths to try to better yourself while such and such is happening.” I always try to affirm their strengths and make them feel like there are better things ahead. I try to get them to a point where it does not matter what anyone else thinks about them. So we deal with that in support group, talking it out amongst each other and doing role-plays, which they really love. The role-plays help them cope with situations they may have faced before and are going to face again. So the next time they will know how to handle it a little bit better.
Modeling through peer support

Some staff members expressed the importance of sharing their own personal experience in living with HIV with clients, especially with clients who were not in care. They believe it helps clients to know that there is another person with the same cultural and social background that has faced similar challenges and is living a normal healthy life with the disease.

LUPITA: I hope that I am playing a good, positive role in their lives and showing them that you can live a normal, healthy life with HIV and still do the things that you want to do. I don't sugarcoat things; I let them know how things really are and how they have been for me. You know, a lot of the

women come to me because they know that I'm married, and they ask me about it. I'm honest with them and I say, no, it's not easy because with me being a positive person and my husband being a negative person, it's difficult. But if you work hard and you put all that you have into it, it can work. So I'm hoping that I'm a positive influence on them and that they look to me for guidance and support. I always try to be a positive person and try to lead by example.

VAUGHN: At the beginning, he didn't care about appointments because he thought he was going to die. Because he didn't have enough information about his disease, we worked together and he learned a little more about HIV and AIDS, the symptoms, medications, and what he can do to live like any other person. Then there was a very dramatic change. I think that the fact that I make my status known serves as proof of the value of obtaining medical care and taking medication. More than anything, being honest has helped a lot.

Connecting with family and friends

Several staff members also made contact with clients’ families and friends to help reconnect with clients. Many contacted family members to relay information about services or to clarify information about HIV disease, or to help them advocate with their family member to seek care.

VAUGHN: With him, I work mostly with his wife. She is the one pushing him to go to all appointments. To him, it is not that important. So we began changing that perception. There were many things that he didn't know, as far as how it's transmitted, and I think that if he did not have his wife, he would do nothing about it.

EUGENE: I think he stayed with us because of my connection to his wife and my asking about him every time I saw her. Things like, “How is he doing? Is he going to go get those bloods? I'd love to see him. Can I come see him when he comes to [the outreach program]?”

Providing emotional support and coaching

Staff members described their process as listening to clients, finding out where they are and where they want to be, and providing constant support and affirmation that they can achieve their set of goals.
CLIFFORD: I was a coach. I told him how the little things he does make a big difference and constantly gave him affirmation that he was still doing a good job. Even though he may have missed his meds one morning, the fact that he remembered to take them that afternoon was a really big deal. I helped him get organized. I was a listener. I think all those things made it go well with us.

**Being consistent and accessible**

Once clients were connected with care, keeping them in care was another challenge. To maintain the relationship, staff consistently followed up with the client and/or family and friends. Many staff members reported that the key to their success was the client’s knowledge that someone would be available to assist with problems or just be there to talk.

QUESTA: I have another client who was dealing, living in a boarded up house with no power, and we wrote him a reminder card for his doctor’s appointment and he remembered the date. Even in the wintertime last year when it was zero degrees, he was standing on his normal street corner and said, “I’m hanging here because I knew you were going to come by looking for me. I wanted to make sure I was around so you’d find me.”

FIONA: Crack tears the system down anyway—it can take a two hundred and fifty pound man and turn him into a hundred pound man. Now when you have that, plus the fact that he’s not getting medical care, it can be very serious. We have a schedule every week, so whether they allow us to service them the first, second, third or fourth time, they’re going to constantly see us, and then they’re going to hear what the outreach program has done for other people. They’re going to see people moving out, they’re going to be seeing people growing, and hopefully want to do the same.

**Working in teams**

Many staff members described the importance of working in teams as a critical strategy for engaging the hard to reach. Teamwork can be a formal process in which staff members with different roles in the same agency are paired together (e.g., a case manager and an outreach worker, or a medical provider and an outreach worker) or informally where a team of providers at the same agency or across agencies work together to support clients. By working in teams, clients received the benefits of a variety of skill sets from each staff member. Also, when one staff person could not reach or connect with a client, perhaps another person would be successful.

**Conclusion**

As these narratives demonstrate, there is no single strategy that works best to reach people who are not in care and engage them in care and treatment. Rather it is a combination of strategies: the ability to go out and find people; to provide services that address clients’ most urgent needs in addition to medical care; to help people learn how to navigate the health care system, improve...
their knowledge about living with the disease, and empower them to obtain the necessary services; to build a relationship that promotes change in health behaviors and promotes the self-acceptance and confidence to live with and manage HIV; and in the process, take an approach that is client-centered and supported.

Some of these services are provided by HIV case managers, especially connecting people to services, delivering HIV education, and relationship-building. However, many HIV case managers have caseloads that are too large and do not allow sufficient time for conducting case-finding activities, accompanying people to appointments, connecting with family members, or maintaining constant contact and availability, particularly for those who individuals who are not connected to health care services. Most resources available to support HIV care at the federal, state, and local level are allocated to reimburse for medical care and prescription drugs. These resources are essential to ensure people living with HIV and AIDS receive appropriate medical care and treatment. However, people who live on the margins of society do not enter care because it is not a priority, or use care sporadically due to negative experiences with providers or beliefs and life circumstances that make it difficult to access HIV care. The people who work directly with people living with HIV and AIDS to facilitate access to HIV care as described above are essential to ensure appropriate HIV care and treatment for all.

There is no single strategy that works best to reach people who are not in care and engage them in care and treatment. Rather it is a combination of strategies...
Despite their diversity in strategies, all of the programs funded under the HRSA/SPNS Outreach Initiative demonstrated measurable effectiveness in engaging and retaining hard-to-reach HIV-infected individuals in medical care. The programs designed interventions to reduce the barriers to care for people facing multiple challenges, improved the coordination of a fragmented social service and healthcare system, and built personal relationships with clients in order to facilitate and promote positive behavior change and optimal use of HIV care and treatment. In achieving these goals, the following are some final points to consider when offering engagement and retention services.

**Short-term, transitional services**
Engagement and retention services are designed to be transitional services—short-term and time-limited, with the goals of connecting people to regular care and, when possible, social stabilization. However, while some people require more time than others to become engaged, it is not known what the time limits of the intervention should be. Preliminary evidence suggests that six months is not enough time for some people, while for others it is all that is necessary. As described by several of the programs from the Outreach Initiative, the amount of time can vary based on a person’s attitudes, behaviors, and the life circumstances affecting their level of social stability. Absent additional research, outer limits of time are likely to be determined by funding levels.

**Location of service**
Engagement and retention services can be delivered in clinics or by community-based organizations, and there are strengths and weaknesses to both approaches. Clinic-based interventions in the Outreach Initiative only reached those who presented themselves for care at some point in time—they did not reach those who had never sought care or were lost to follow-up. However, the clinic-based interventions were very effective in targeting resources to serve people who had a history of tenuous connection to care or fit the profile of those who had dropped out of care in the past. The clinic-based interventions also faced challenges in integrating their services into the operations and culture of the clinic, yet one program (Whitman-Walker Clinic) found a way to do this very successfully. Finally, the clinic-based interventions spent less time, or none at all, in the community on their clients’ own turf. We have no evidence that time in the community strengthens the outcome of improving engagement and retention in care, but the experience of the community-based programs suggests that this capacity may be critical for people with very complex life circumstances.

Community-based interventions were able to reach out to those who had never sought care or were lost to follow-up, but had a hard time finding these individuals without strong linkages to counseling and testing sites, clinics, or other community-based organizations. Community-based interventions with a strong clinic partnership may have an easier time finding individuals, particularly if staff members are able to spend time in the community to build relationships with people who are not yet ready to enter care. But program staff still have to negotiate clinic relationships and build credibility for the intervention with clinical providers to make the intervention successful.
Relationship with case management
Nearly every intervention included functions that overlapped with those provided by case managers. In some programs, the engagement and retention staff functioned fully as case managers (Project Bridge, Well-Being). In other programs, intervention staff worked closely with other case managers to prevent overlap and duplication of effort (CareLink/Cascade AIDS Project, Konnect II/POCAAN, Whitman-Walker Clinic). In the Drew University program, intervention staff functioned in both roles depending on the client’s existing case management support system. Where programs did not provide case management services directly, staff devoted considerable energy to forming strong relationships with case managers, good communication strategies, and formal mechanisms for communication and information sharing. This was not an easy task for most programs and required significant time and the attention of program managers as well as front-line staff.

Relationships with other providers in the continuum of care
In addition to case managers, all of the programs described the importance of establishing close relationships with other service and medical providers, either within their own organization or within their community, to connect with hard-to-reach HIV-infected people. Because of the complex life circumstances of their clients, most programs connected with agencies providing basic services such as housing, food, clothing, and other practical support—especially for people who were out of medical care.

Because of the complex life circumstances of their clients, most programs connected with agencies providing basic services such as housing, food, clothing, and other practical support—especially for people who were out of medical care.

Other programs connected with counseling and testing agencies to ensure the newly diagnosed were immediately connected to medical care or with agencies working with high-risk populations for HIV such as the ex-incarcerated, active substance users, or the homeless. For clinics, this required strengthening provider relationships across departments and ensuring open communication between medical and social service staff about the necessary steps needed to keep the client in care and adhering to treatment. For community-based organizations, it often required significant time developing Memoranda of Understanding across partners and devoting staff resources to attend meetings and host events to keep partners informed and updated on the program’s services.

By forming these relationships, HRSA/SPNS Outreach Initiative programs were able to build a network of providers for the client. Thus when confronted with an issue that could affect a client’s receipt of medical care, there was a team approach to address the issue and keep the client in care.

Staff qualifications and characteristics
The staff involved in the programs of the Outreach Initiative included clinicians, paraprofessionals, and peers. All were suc-
cessful in engaging and retaining individuals in HIV medical care, but they brought different strengths and weaknesses to this task. Nurses and licensed social workers were able to provide state-of-the-art clinical information or mental health counseling to their clients and had a certain level of credibility with health care providers when they accompanied clients to medical appointments. In these demonstration projects, the clinical staff also did a phenomenal job of building relationships with clients, gaining their trust to take the next step in accessing care without being judgmental about drug use or lifestyle differences. They also spent most of their time in the community, meeting clients on their own turf and helping clients navigate health and social service systems. This capacity may be testimony to the unique character, skills, and personal styles of the individuals who chose to do this work.

The paraprofessionals involved in the demonstration projects may not have had the clinical training of the professionals, but they received the training necessary to move many of their clients to take the next step in accessing care and had clinical resources available to them when their own skills were not sufficient to meet a client’s needs. Many of the paraprofessionals worked as part of a team that included clinicians, and they provided the non-clinical but very essential services to connect clients with benefits, housing, food, legal services, immigration services, and other basic needs. Although paraprofessionals did not start out with the same credibility as clinicians when accompanying clients to medical appointments, the Whitman-Walker case study shows that this credibility can be gained.

The peers who participated in this demonstration project brought very important qualities to the engagement and retention function. More than any other staff members, peers can provide proof that you can live with the HIV disease; that entering care and receiving treatment can make a difference; that you can reveal your status to others if you think carefully about who should know, how to tell them, and how to protect yourself from adverse reactions; that you can acquire the skills to address stress, stigma and discrimination; that you can live a full and meaningful life; and above all, that there can be a future. In short, peers have an innate ability to form relationships with clients who are looking for proof that change can make a difference because their personal experiences form that proof. Peers who help clients deal with these issues need ongoing training and quality supervision to trouble-shoot difficult situations and help to keep a separation between their own circumstances and those of their clients. Where these circumstances exist, peers can be a very strong asset to engagement and retention interventions.
Contact list for HRSA/SPNS Outreach Initiative programs

CareLink Program
Cascade AIDS Project
620 SW Fifth Avenue, Suite 300
Portland, OR 97204
P: (503) 223-5907
F: (503) 223-7087
www.cascadeaids.org

Alison Frye, Manager Client Outreach and Assessment,
afrey@cascadeaids.org

Caring Connections
University of Miami
1695 NW 9th Avenue,
Room 3308 (D-21)
Miami, FL 33136
P: (305) 355-9182

Sally Dodds
Principal Investigator
sdodds@med.miami.edu

Drew University Mobile Health Outreach Project
1731 E. 120th Street
Los Angeles, CA 90059
P: (310) 763-9746
F: (310) 763-9780
www.cdrewu.edu

Cynthia Davis
Director
cdmom49@aol.com

The Fenway Institute
Fenway Community Health Center
7 Haviland Street
Boston, MA 02115
P: (617) 927-6000
F: (617) 859-1250
www.fenwayhealth.org

Judith Bradford
Principal Investigator
jbbradfo@vcu.edu

Horizons Project
Wayne State University
Department of Pediatrics
4201 St. Antoine
UHC-6E.15
Detroit, MI 48201
P: (313) 966-9763
F: (313) 745-4004

Monique Green Jones
Program Manager
mogreen@med.wayne.edu

Sylvie Naar-King,
Prinicipal Investigator,
snaarkin@med.wayne.edu

Konnect II Client Advocacy Program
People of Color Against AIDS Network (POCAAN)
2200 Rainier Avenue South
Seattle, WA 98144
P: (206) 322-7061
F: (206) 322-7204
www.pocaan.org

Aaliyah Messiah
Program Director
aaliyah@pocaan.org

Maria Enriquez Lindsey
Research Assistant
maria@pocaan.org

Project Bridge,
The Miriam Hospital
369 Broad St.
Providence, RI 02906
P: (401) 455-6789
F: (401) 455-6793

Leah Holmes
Principal Investigator
Iholmes@lifespan.org

Well-Being Institute
3800 Woodward Ave, Suite 1010
Detroit, MI 48201
P: (313) 615-0400
F: (734) 913-4306

Geoffrey Smereck
Principal Investigator
gads@pnc-wbi.com

Whitman-Walker Clinic
1701 14th St. NW
Washington, DC 20009
P: (202) 745-6149
F: (202) 745-0238
www.wwc.org
Appendices

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### Outreach encounter form

**Date of Encounter:** ______/______/______

**Outreach Worker(s) Initials:** ____________________

**Number of Outreach Workers:** __________

**Location of Contact (check one)**

<table>
<thead>
<tr>
<th>Location</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Streets, parks, open space</td>
<td>1</td>
</tr>
<tr>
<td>Mobile van</td>
<td>2</td>
</tr>
<tr>
<td>Client house or apartment</td>
<td>3</td>
</tr>
<tr>
<td>Client non-permanent residence (shelter, SRO)</td>
<td>4</td>
</tr>
<tr>
<td>Outreach program office</td>
<td>5</td>
</tr>
<tr>
<td>Other social service agency</td>
<td>6</td>
</tr>
<tr>
<td>Medical setting (clinic, hospital)</td>
<td>7</td>
</tr>
<tr>
<td>Residential treatment program</td>
<td>8</td>
</tr>
<tr>
<td>Correctional setting</td>
<td>9</td>
</tr>
<tr>
<td>Other community setting (bar, club, drop-in ctr)</td>
<td>10</td>
</tr>
<tr>
<td>Other (specify): ______________________</td>
<td>11 &amp; OTHRLOC</td>
</tr>
</tbody>
</table>

**Not Applicable (not face-to-face)**: 12

**Purpose/Content of Outreach Encounter (check all that apply)**

<table>
<thead>
<tr>
<th>Content</th>
<th>Code</th>
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</thead>
<tbody>
<tr>
<td>Provide information about the program</td>
<td>INFOPROG</td>
</tr>
<tr>
<td>Provide general HIV education</td>
<td>GENHIV</td>
</tr>
<tr>
<td>Provide specific HIV risk reduction/counseling</td>
<td>SPEHIV</td>
</tr>
<tr>
<td>HIV or STD testing</td>
<td>HIVSTD</td>
</tr>
<tr>
<td>Provide information about HIV medications</td>
<td>INFOHIVM</td>
</tr>
<tr>
<td>Appointment reminder</td>
<td>APPTREM</td>
</tr>
<tr>
<td>Appointment rescheduling</td>
<td>APPTRSCH</td>
</tr>
<tr>
<td>Provide concrete services (e.g., provide transport for errands, food/ transport vouchers)</td>
<td>CONCR</td>
</tr>
<tr>
<td>Provide harm reduction supplies (condoms, bleach)</td>
<td>HRS</td>
</tr>
<tr>
<td>Relationship-building</td>
<td>RELBUILD</td>
</tr>
<tr>
<td>Accompany client to medical appointment</td>
<td>ACCMED</td>
</tr>
<tr>
<td>Accompany client to other appointment</td>
<td>ACCOTHR</td>
</tr>
<tr>
<td>Provide assistance with benefits/entitlements</td>
<td>PROVASST</td>
</tr>
<tr>
<td>Refer to or make appointment for health care</td>
<td>REFHC</td>
</tr>
<tr>
<td>Refer to or make appt. for housing services</td>
<td>REFSH</td>
</tr>
<tr>
<td>Refer to substance abuse treatment</td>
<td>REFAB</td>
</tr>
<tr>
<td>Refer to needle exchange</td>
<td>REFNE</td>
</tr>
<tr>
<td>Refer to or make appt. for mental health care</td>
<td>REFMH</td>
</tr>
<tr>
<td>Refer to or make appt. for other services</td>
<td>REFOTHR</td>
</tr>
<tr>
<td>Provide medical services</td>
<td>PROVMEDS</td>
</tr>
<tr>
<td>Provide mental health counseling</td>
<td>PROVMENT</td>
</tr>
<tr>
<td>Provide other counseling</td>
<td>PROVOTH</td>
</tr>
<tr>
<td>Provide service coordination</td>
<td>SRVCCRDN</td>
</tr>
<tr>
<td>Provide crisis intervention</td>
<td>CRSINTRV</td>
</tr>
<tr>
<td>Perform client needs assessment</td>
<td>CLNTNEED</td>
</tr>
<tr>
<td>Advocate for client</td>
<td>ADVCLNT</td>
</tr>
<tr>
<td>Refer to or make appointment for dental services</td>
<td>DENTAL</td>
</tr>
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**Other (specify): ______________________ | O & OTHRLOC |

**Duration of Contact (check one)**

<table>
<thead>
<tr>
<th>Duration of Contact</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempted Contact*</td>
<td>0</td>
</tr>
<tr>
<td>&lt; 5 minutes</td>
<td>1</td>
</tr>
<tr>
<td>6-14 minutes</td>
<td>2</td>
</tr>
<tr>
<td>15-29 minutes</td>
<td>3</td>
</tr>
<tr>
<td>30-59 minutes</td>
<td>4</td>
</tr>
<tr>
<td>1 hour - 1 1/2 hours</td>
<td>5</td>
</tr>
<tr>
<td>1 1/2 - 2 hours</td>
<td>6</td>
</tr>
<tr>
<td>&gt;2 hours</td>
<td>7</td>
</tr>
</tbody>
</table>

*Check only if you left a message regarding a medical appointment or referral to any HIV services.

**Type of Contact (check one)**

<table>
<thead>
<tr>
<th>Type of Contact</th>
<th>Code</th>
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</thead>
<tbody>
<tr>
<td>Face-to-face</td>
<td>1</td>
</tr>
<tr>
<td>Telephone</td>
<td>2</td>
</tr>
<tr>
<td>Letter</td>
<td>3</td>
</tr>
<tr>
<td>Email/Internet</td>
<td>4</td>
</tr>
<tr>
<td>Collateral Contact</td>
<td>5</td>
</tr>
</tbody>
</table>

**Other (specify): ______________________ | 6 & OTHRTYPE |

**Note:** Please erase, white-out or cut out these notes before submitting to CORE.

**Client ID:** ______________________

**Client ID:** ______________________

**Outreach Staff Code(s) (circle all that apply)**

<table>
<thead>
<tr>
<th>Staff Code</th>
<th>Code</th>
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<tbody>
<tr>
<td>Peer Outreach worker</td>
<td>POW 1</td>
</tr>
<tr>
<td>Non-peer Outreach worker</td>
<td>NPOW 2</td>
</tr>
<tr>
<td>Case Manager CM</td>
<td>3</td>
</tr>
<tr>
<td>Social Worker SW</td>
<td>4</td>
</tr>
<tr>
<td>Mental Health Clinician</td>
<td>MHC 5</td>
</tr>
<tr>
<td>Substance Abuse Counselor</td>
<td>SAC 6</td>
</tr>
<tr>
<td>Nurse N</td>
<td>7</td>
</tr>
<tr>
<td>Physician P</td>
<td>8</td>
</tr>
<tr>
<td>Nurse Practitioner/Physician Assistant NPPA</td>
<td>NPPA 9</td>
</tr>
<tr>
<td>Administrative Staff AS</td>
<td>AS 10</td>
</tr>
<tr>
<td>Client Volunteer CV</td>
<td>11</td>
</tr>
<tr>
<td>Staff Volunteer SV</td>
<td>12</td>
</tr>
</tbody>
</table>

**Other (specify): ______________________ | O & OTHRSTAF 13 |

**Health Resources and Services Administration (HRSA) SPNS Outreach Initiative Developed by the Center for Outreach Research and Evaluation, BU School of Public Health.**

76 • Making the Connection
### Weekly progress log for tracking clients

<table>
<thead>
<tr>
<th>Category</th>
<th>Baseline Progress</th>
<th>Baseline Intervention Progress</th>
</tr>
</thead>
<tbody>
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<td>__________</td>
<td># complete: __________</td>
</tr>
<tr>
<td># scheduled:</td>
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<table>
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<td>__________</td>
<td># scheduled: __________</td>
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<tr>
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<td>__________</td>
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<tr>
<td># trouble*:</td>
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<tr>
<td># pending:</td>
<td>__________</td>
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<table>
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</tr>
<tr>
<td># scheduled:</td>
<td>__________</td>
<td># scheduled: __________</td>
</tr>
<tr>
<td># missed*:</td>
<td>__________</td>
<td># missed*: __________</td>
</tr>
<tr>
<td># trouble*:</td>
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</tr>
<tr>
<td># pending:</td>
<td>__________</td>
<td># pending: __________</td>
</tr>
</tbody>
</table>
Structure of the standard MI session

Ensure that readiness ruler is administered just before session, ideally by someone other than you.

Opening statement
» I’m not here to preach to you or tell you what you “should” do; how would I know, it’s your life and not mine! I believe people know what’s best for them.
» I don’t have an agenda, just a goal: to see if there is anything about the way you take care of your health that would like to change, and if so, to see if I can help you get there.
» How does that sound to you?

The Session
Begin with a general question regarding their health and health-related behavior. For example, “I’m curious—how happy are you with how well you take care of your health?”
» Follow-up by using all your best MI skills: reflections, open-ended questions, affirmations, and eliciting change talk (e.g., “You said you feel you could be doing better. In what way?”). The overall goal, here, is to communicate a genuine desire to understand, not a desire to push them into anything.
» Try to stay focused on health-related behavior. This part should take 5–10 minutes, but could be more or less depending on the client.

Next, mention that you have some information to share, if it’s OK with them. “I’ve got some information here that’s related to you and your health. Is it OK with you if we go over this a minute?”
» Remember the keys to good feedback: be completely objective (you are providing them with information that they can take or leave, you are NOT evaluating them), never argue, and ask a simple question: “What do you make of all this?”
» Follow-up with reflections, etc. Be sure to use the Pros and Cons exercise and at least one other strategy to elicit change talk, usually the Readiness Ruler (“On a 0–10 scale, if 0 is not in the least bit ready to see the doctor at least once every 3 months and a 10 is as fired up as you can be, where are you?). Remember with the Readiness Ruler to ask “Why a 3 and not a 0?” if they give a low number, and “Why such a high number?” if they give a high number (7 or higher).
» Remember, never argue, never push, just be curious and accepting. There’s no hurry. Remember also, the goal here is to maximize change talk by using questions that elicit change talk, by asking for elaboration (if they give a little, ask for more details), and by using exercises like Pros and Cons or the Readiness Ruler.

When there are 5–10 minutes left in your session (or when you feel like you’re not going to get any further with Phase I), move on into Phase II.
» Do a good summary of everything that’s been said so far. “Let me see if I understand where you’re at with your health right now . . .” Summarize the things they feel good about and the positive health behaviors you have noticed, starting with general health stuff and ending with specific stuff about their attending doctor’s appointments. Next move into the things that concern them in general, and things that concern them about appointments in particular. Note, if there is one, the disparity between recommended number of appointments and the number they kept last year. Ask if your summary is about right. If not, correct it.

Ensure that readiness ruler is administered after session, ideally by someone other than you.

Revised 8/6/04
Structure of the values session

Client # ___________________

Values clarification is a more hands-on, inside-out approach to reaching the same goals as in standard Motivational Interviewing: it involves a constructive, non-judgmental conversation about change in which the therapist seeks to understand the perspective of the client, change talk is strategically elicited, and the client is helped to marshal his or her own resources for change, in his or her own way and for his or her own reasons. It is more hands-on, because the client takes on much of the burden of gaining insight via a card sort activity. It is more inside-out, because it begins from core values and moves to beliefs and behavior, rather than vice-versa.

First, remind/reassure client about confidentiality. Then explain to the client that you’d like to know more about what’s most important to them, and that to do that you would like to try a little exercise, if that’s OK with them. Once the client indicates interest, ask him or her to sort the values cards into three piles—most important, important, and not as important to them. Then ask them to rank-order the values in their “most important” pile from most to least important.

This can be very difficult to do! (It’s OK to reflect this if they’re struggling.) Help them to at least identify their top three values. Then initiate a discussion with the following questions. You don’t have to rigidly adhere to these questions or this order, but you should not deviate much. In general, you would only skip a question if the client has already addressed it completely in answering an earlier question.

Ask client which value they want to discuss first.

Values are:
1. __________________________
2. __________________________
3. __________________________

Then, for each value ask:
1. What does______mean to you?
2. How are you doing at living out this value?
3. How much time and effort are you putting into living this value?
4. (If necessary.) What behaviors or attitudes prevent you from achieving this value?

After discussing all three:
1. Part of taking care of you health, according to doctors, is that you attend at least one visit with them every three months, even if things seem to be going OK. Is doing this relevant in any way to your living out these values?
2. Summarize the discussion.
3. (If necessary) What, if anything, do you want to do differently from here on out in order to live out these values the way you would like? –or–
4. Winding down the session, where do you see yourself in the next 5 years and do you see yourself having lived out these values the way you would like.

Client ID # ___________________
Session # ___________________

Use empathic reflection to help you gain (and express!) understanding of what is truly important for this client. Summaries and double-sided reflections may also be quite helpful for the client.

______________________________
______________________________
______________________________
______________________________
______________________________
______________________________

Write below the client’s response to “What behaviors or attitudes prevent you from achieving this value?” for each value here.

______________________________
______________________________
______________________________
______________________________
______________________________
______________________________

Write below the client’s responses to “What, if anything would you like to do to from here on out in order to live these values the way you would like” after you have discussed all three values.

______________________________
______________________________
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Revised 12/3/04
**MITI coding sheet**

**Tape #____________**  **Coder/Supervisor: ________________________________________________**

**Segment Start:____________**  **Segment End:____________**  **Session Type: MI**  **Other:____________**

### Global Ratings

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### Behavior Counts

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<td>Asking permission, affirm, emphasize control, support.</td>
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<td>Advise, confront, direct.</td>
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<td>TOTAL REFLECTIONS (RF)____</td>
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</tbody>
</table>

**First sentence:______________________________________________________________ (Therapist or Client)**

**Last sentence:______________________________________________________________ (Therapist or Client)**

% Complex Reflections (%CR) = Rc/Total RF = ________________________________

Reflection-to-Question Ratio (R:Q) = Total RF/Total Q = ____________________________

% MI Adherent (%MiA) = MiA / (MiA + MiNa) = ________________________________

% Open Question (%OC) = OQ/Total Q = ________________________________
Global Rating of Motivational Interviewing Therapist (GROMIT)  
(Moyers, 2004)

<table>
<thead>
<tr>
<th>The therapist...</th>
<th>Do not agree</th>
<th>Somewhat agree</th>
<th>Fully agree</th>
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<tr>
<td>1) ... provided feedback in an objective fashion rather than trying to use information to persuade the client.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>2) ... avoided power struggles when possible and allowed clients to 'win' when resistance was encountered.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3) ... showed an understanding of the client's point of view.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>4) ... showed confidence in the client's ability to make changes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>5) ... guided the client toward verbalizing the need for change instead of telling the client why change was needed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6) ... expressed interest in the client's values and goals in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7) ... attempted to persuade the client about the seriousness of the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8) ... argued with the client.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9) ... assumed the expert role.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10) ... actively encouraged the client to contribute ideas about how to change the target behavior.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11) ... expressed disapproval of the client.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12) ... directed the client's attention toward their own strengths.</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13) ... seemed phony.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14) ... recognized change talk from the client and responded appropriately to it.</td>
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<td>3</td>
</tr>
<tr>
<td>15) ... steamrolled the client.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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Notes:
This Memorandum of Agreement is between People of Color Against AIDS Network (POCAAN) Konnect II Program and ________. This memorandum outlines the working relationship between these two agencies/programs as it concerns the Konnect II Client Advocacy Program funded under the Ryan White CARE Act/Congressional Black Caucus Minority Initiative.

The goal of this relationship is to coordinate and collaborate on improving health care outcomes for persons of color newly diagnosed with HIV and/or who have been diagnosed and are at risk of dropping out of the care system.

1. POCAAN/Konnect II agrees to:

   a. Provide primary care services to HIV+ clients referred by POCAAN/Konnect II.

   b. Support and respect the uniqueness of the relationship between advocate and client based on race, culture and language in order to enhance the services provided to the client.

   c. Ensure that clients referred by POCAAN/Konnect II sign a Release of Information disclosure form to permit the sharing of information between primary care provider and client advocate necessary to facilitate successful engagement into treatment and to fulfill the data obligations of this grant. This form will allow client’s information about their HIV/AIDS testing and treatment, drug and alcohol use, mental health status and history, and STD test results and treatment to be shared. It is understood that consent to share information will terminate in 90 days from the date of signature.

   d. Work with clients to orient them to the care system, clarifying the role of the primary care provider in contrast to the role of the client advocates and peer supporters.

   e. Help facilitate the orientation of the client advocates and peer supporters in understanding the procedures and process that clients undergo upon referral/intake and during ongoing care.

   f. Primary care providers will help clients access medical care and related social services by assisting them to arrange appointments and tracking them through their initial appointments to help ensure a positive experience.

   g. Provide African American and Latino HIV+ clients with information about POCAAN/Konnect II’s support groups and health education meetings.

   h. The primary care provider will contact the client advocate if s/he is concerned that a referred client is at risk to drop out of care or services or has missed two (2) consecutive appointments without rescheduling.

   i. Provide documentation as requested on the Quarterly Evaluation Follow-Up form for all referred clients with current Release of Information.

   j. Ensure that all personal identifying information obtained in connection with the delivery of services will not be disclosed unless required by law or unless such a person provides written, voluntary informed consent.

2. POCAAN/Konnect II agrees to:

   a. Refer HIV+ people of color to ________ for primary care and/or case management.

   b. Support and respect the relationship between primary care provider and client, recognizing that this relationship is based on knowledge about the client’s medical, psychosocial, substance use and mental health status and history. This relationship is also based on the primary care provider’s training, knowledge and experience in mental illness, substance use, medical and treatment aspects of HIV, and the appropriate and diligent use of resources.

   c. Ensure that clients referred by POCAAN/Konnect II sign a Release of Information disclosure form to permit the sharing of information between primary care provider and client advocate necessary to facilitate successful engagement into treatment and to fulfill the data obligations of the grant. This form will allow client’s information about their HIV/
AIDS testing and treatment, drug and alcohol use, mental status and history and STD test results and treatment to be shared. It is understood that consent to share information will terminate 90 days from date of signature.

d. Work with primary care providers to orient clients to the care system, clarifying the role of the client advocates in contrast to the role of primary care providers. Client advocates will help clients access medical care and case management by assisting them to arrange appointments and may accompany clients to these appointments. Client advocates may also assist clients to make initial contact with some resources. Concerns about mental health, substance use, income and medical benefits and the need for housing and emergency grants will be discussed with the primary care provider who will manage referrals to these resources with the support of the client advocate.

e. Follow-up and assess clients who have dropped out or are at risk of dropping out of services to determine why and to provide support to these individuals to re-link them to primary care.

f. Client advocates will provide educational feedback to primary care providers that support the culturally appropriate treatment of clients and helps ensure that medical care and primary care is sensitive to each individual's racial, cultural, and language issues.

g. Provide on-going one-on-one support through peer supporters who are HIV+ and can identify with clients. Peer Supporters shall be African American and Latino/a and will work in conjunction with the African American and Latino/a Client Advocate to enhance the support, referral and help network in order to address client needs.

3. Term, Indemnity, and Miscellaneous

a. This agreement is in effect and will remain in effect for the duration of the Ryan White CARE Act funding. This agreement may be cancelled without cause by any of the parties upon 30 days' written notice or by mutual consent of all the parties at any time.

b. Dispute resolution: If at any time a conflict or dispute arises between the primary care provider and the client advocate, or between any other staff of either agency named in this agreement, the dispute will be brought to the respective supervisors for resolution. If the situation cannot be satisfactory resolved at that level, or if the supervisors are involved in the dispute, both agencies will refer the issue to the next person in the chain of responsibility. If resolution is still not possible, a mutually agreed upon mediator will be identified to help resolve the conflict.

It is hereby agreed that these are acceptable terms on behalf of both agencies.

______________________________
Aaliyah Messiah,
Program Manager Konnect II

Printed name

______________________________
Date

______________________________
Printed name

______________________________
Date
I. Introduction: This agreement between Bienestar Human Services (Bienestar), Charles R. Drew University of Medicine and Science's Educational Outreach and HIV Mobile Testing Project (Drew), and University of California Los Angeles (UCLA), Division of General Internal Medicine (GIM) represents the intent of all three entities to work collaboratively on the HIV Outreach and Access to Care project. Bienestar Human Services is a private non-profit organization dedicated to developing, delivering, and evaluating culturally sensitive, comprehensive service models that empower and advocate for high risk families. Charles R. Drew University of Medicine and Science's HIV Mobile Testing Project has provided free HIV antibody testing services since 1992 to the African-American and Latino populations residing in South Central Los Angeles. UCLA GIM is dedicated to understanding and improving access to care for vulnerable populations.

II. Statement Of Project Concept: Bienestar Human Services proposes to collaborate with the Drew University HIV Mobile Testing Project and with UCLA GIM in recruiting HIV positive persons for their project on outreach and access. The target population will be poor, minority or underserved persons with HIV who lack access to HIV care or encounter delays in accessing care. The target area will be central Los Angeles County in California. Services to be provided by Drew will include the following: outreach, assessment and referral, case-management brokerage of support services including HIV/AIDS education and risk reduction, HIV counseling, substance abuse treatment, and support services.

III. Program Goals: The focus will be as follows: identify HIV-infected individuals in Los Angeles through existing HIV testing and counseling provided by the Bienestar and Drew mobile HIV testing van program, and to engage and retain these identified HIV-infected individuals into medical care through Outreach and Access project run by Drew and UCLA GIM. Furthermore, the program will offer case-management referral services to those who need them, to reduce barriers and improve service delivery. Thus, the program aims to promote engagement and retention in HIV care, and foster improved health outcomes.

IV. Responsibilities Of Bienestar Human Services: Bienestar Human Services will have the responsibility for: identifying and recruiting potential participants, who are HIV positive. Gustavo Arguellas of Bienestar will inform potential participants about the study and, if persons are interested, make referrals to Cynthia Davis of Drew for potential recruitment.

Cynthia Davis of Drew, HIV Mobile Testing Project will have the responsibility for: screening potential clients for recruitment; conducting participant interviews; obtaining informed consent; provide client routine HIV/AIDS education, risk reduction and behavioral change counseling; provide social support and case management services, if needed. Drew University will also provide staff to conduct these activities and Cynthia Davis will supervise them.

V. Responsibilities Of Collaborator: Drs. Cunningham and Mitchell Wong of UCLA will be responsible for overseeing all evaluation activities including interviews, data entry, and analysis.

VI. Period Of Agreement: This Memorandum of Understanding and any amendment thereof shall remain in effect until terminated by either party by written notice by an authorized agent of either organization.

Brenda Padilla
Bienestar Human Services

Cynthia Davis, MPH
Program Director
Drew HIV Mobile Testing

William Cunningham, MD, MPH
Principal Investigator
University of California, Los Angeles
## CID = MM1001

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<th>Status</th>
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<th>Rec’d Reason</th>
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## Case management daily log

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<th>Col.</th>
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</table>

Worker: ____________________________
In care form

To be completed every 3 months

Client: ___________________________________________ Date: _______/_____/_______

Date of HIV diagnosis: _______/_____/___________________

Person completing form: ________________________________________

To be considered “In-Care” 4 out of the 5 criteria must be documented

☐ Client has medical insurance or has applied for coverage
  ☐ Medicaid# ____________________________ ☐ Private Insurance: ____________________________
  (name)
  ☐ Medicare A & B# ____________________________ ☐ OMIP# ____________________________
  ☐ VA Insurance # ____________________________ ☐ Applied for: ____________________________
  (insurance type)

☐ Client is regularly attending case management appointments based on acuity level
  Name of Case Manager: ____________________________
  Date of last contact: _______/_____/_______
  ☐ Appropriate participation verified with CM: ______________

☐ Client is regularly attending medical appointments based on medical need
  Name of provider: ____________________________
  Date of last contact: _______/_____/_______
  ☐ Verified with provider/CM team: ______________

☐ Client knows what viral load and CD-4 count mean

☐ Client has had a viral load and CD-4 count within the last 3-6 months, based on medical need
  Viral load: ____________________________ Date: _______/_____/_______
  ☐ Verified with Provider/CM team: ______
  CD-4 count: ____________________________ Date: _______/_____/_______

Number of criteria met: ____________________________ Date: _______/_____/_______

Care status:       baseline: out of care at-risk
                  follow-up: not yet connected in-care

continues »
Access barriers
(i.e., barriers that put someone at high risk for not engaging or for falling out of care) include one or more of the following:

- Primary language other than English.
- Active or recent substance abuse issue.
- Active or recent mental health issue.
- Recent or chronic incarceration
- Homeless or in unstable housing.
- Lack of health insurance combined with no case manager.
- History of disconnecting from care (this includes those who are newly diagnosed and haven’t engaged in care within three months).

Dental care

**Are you interested in dental care?**

- Yes
- No

- Russell Street contacted by client/you for appointment
- Russell Street added to ROI
- Team Lead given client name