Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care

January 2013
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The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has developed the Integrating HIV Innovative Practices (IHIP) manuals, curricula, and trainings to assist health-care providers and others delivering HIV care in communities heavily impacted by HIV/AIDS with the adoption of Special Projects of National Significance (SPNS) models of care. This IHIP training manual is part of that effort. Additional IHIP materials can be found at [www.careacttarget.org/ihip](http://www.careacttarget.org/ihip).
The Ryan White HIV/AIDS Program, administered by the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), has a demonstrated track record for delivering culturally competent and comprehensive HIV services to marginalized and underserved populations nationwide over the past 20 years. HRSA currently is bringing its wealth of experience to the implementation of the National HIV/AIDS Strategy (NHAS).\(^1\)

Released by the White House Office of National AIDS Policy (ONAP) in July 2010, the NHAS provides a roadmap to mitigating and ultimately ending the HIV/AIDS epidemic in the United States crystalized in three goals that also speak directly to the mission of the Program:

1. **Reduce the number of people who become infected with HIV.**
2. **Increase access to care and improve health outcomes for people living with HIV/AIDS (PLWHA).**
3. **Reduce HIV-related health disparities.**\(^2\)

The NHAS calls on interagency cooperation at all levels in order to significantly reduce new infections and to increase the number of people who know their serostatus.\(^3,4\) HRSA is charged with engaging newly diagnosed PLWHA into clinical care sooner and increasing the number of clients who are already aware of their HIV status into continuous HIV primary care.\(^2\)

HRSA is a natural leader for these NHAS efforts. Nearly one-half of the estimated 1.2 million PLWHA in the United States—approximately 529,000—access HIV services through the Ryan White HIV/AIDS Program.\(^5\) Established with the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, the Program operates differently from other Federal medical programs. It serves as the payer of last resort, providing coverage and filling in gaps for PLWHA who do not have sufficient health insurance and/or financial resources for HIV/AIDS treatment, care, and support services. Funds are awarded directly and indirectly to

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**SCOPE OF THE PROBLEM**

You can never underestimate the importance of the person delivering an HIV diagnosis or providing those initial linkages to services. That encounter alone may mean the difference between someone entering and not entering care.

—Lisa Hightow-Weidman, University of North Carolina, Chapel Hill, School of Medicine
service providers, ranging from community-based HIV clinics to large metropolitan hospitals.

The Program's Special Projects of National Significance (SPNS) has developed numerous innovative models to engage hard-to-reach PLWHA into care. HRSA supports the evaluation of these efforts and assists with dissemination of research resulting from each project.

HRSA has developed the Integrating HIV Innovative Practices (IHIP) manuals, curricula, and trainings to assist health-care providers and others delivering HIV care in communities heavily impacted by HIV/AIDS with the adoption of SPNS models of care into their practices. This IHIP training manual provides:

- An overview of hard-to-reach populations most impacted by HIV and the barriers they face to accessing HIV prevention, testing, treatment, and care, as well as ancillary services.
- An overview of best practices distilled from extensive research available on these SPNS Program initiatives. The potential benefits and challenges associated with each of the models of care are discussed, along with costs and other logistical issues.
- A list of resources and other useful information to further assist with the replication process.

The need for innovative approaches to engaging hard-to-reach populations cannot be overstated. According to the U.S. Centers for Disease Control and Prevention (CDC), many PLWHA are not in care and 20 percent of HIV-positive persons in the United States are unaware of their serostatus. Without intervention, these PLWHA most likely will progress to AIDS, undermining their health outcomes, quality of life, and life expectancy. Replication of SPNS models by HIV providers will help to identify and engage PLWHA into care, as well as mitigate the impact of HIV nationwide—improving the quality of life for communities hardest hit by the epidemic and saving countless lives.
HRSA conceptualizes engagement in HIV care as a spectrum, as opposed to a singular event, that begins with PLWHA learning their serostatus and ends with their full engagement and retention in HIV primary care (see Figure 1 on page 4). Numerous factors prevent PLWHA from moving smoothly from one end of the spectrum to the other. For instance, a large number of PLWHA have never been screened for HIV, and others have been tested but never learned their results. Still other PLWHA know their status but have not been referred to care; have never followed up on their referral; are in care, but not for HIV; or have fallen out of HIV care or seek it sporadically due to a variety of reasons. The location of PLWHA along the spectrum is not static. Rather, they move up and down the continuum in response to unmet needs, such as those related to food insecurity and shelter instability (FISI), poverty, substance use disorders (SUDs), mental illness, and other psychosocial and economic determinants. PLWHA

“...the door to darkness had been opened, and all the taboos were out there—sex, death, homosexuality, drug use. Things that people had never heard discussed openly before.”

–Cliff Morrison, who established Ward 5B/5A at San Francisco General Hospital in the early days of the epidemic

“You hear stories that people are still very much ashamed to have HIV due to religious beliefs and cultural stigma. People view the disease with a lot of disdain and blame those who are living with it. There are certainly huge barriers that still exist [to testing and care].”

–Michael K. Evanson, senior policy analyst in the Division of Science and Policy at HRSA, HAB
with limited educational attainment and histories of incarceration also have difficulty obtaining and maintaining employment and health insurance, which can further delay them in accessing care. It is not uncommon for PLWHA to ignore their health needs until they require emergency room assistance. Seeking assistance from an HIV primary care provider often marks their first ongoing experience with the health-care system.8

The need for PLWHA to seek HIV treatment as soon as possible in their infection cannot be overstated. Research has shown consistently that PLWHA who are engaged in a holistic spectrum of care, such as that offered by Ryan White HIV/AIDS Program providers, are more motivated to keep appointments; initiate and adhere to antiretroviral therapy (ART); regularly get required lab work done; and participate in support services, such as mental health, SUD and alcohol counseling, and dental care. They, along with their families, also are more likely to leverage ancillary/wraparound services facilitated by Program providers, such as transportation, food and clothing banks, and health education classes.9–13

Early HIV intervention and treatment improve PLWHA health outcomes. Costs of early interventions are also significantly cheaper—sometimes by more than 50 percent—than those associated with late HIV infection and end-of-life care.14,15 Moreover, PLWHA in care are less likely to engage in high-risk behaviors, such as unprotected sex and injection drug use (IDU), which decreases transmission of HIV and comorbidities such as hepatitis. These PLWHA are also more likely to take their ART consistently, mitigating their chances of becoming resistant to HIV medications and progressing to AIDS.16–19

Despite the potential for these positive health outcomes, a large number of PLWHA do not engage in care, or fall out of care shortly after starting it. For instance, approximately 35 to 45 percent of PLWHA are tested for HIV later in their infections, as indicated by their diagnosis with both HIV and AIDS and/or progression to AIDS within a year of their HIV diagnosis. These late testers most likely have had HIV for longer than 5 years, during which their immune system as well as potential success in ART have been significantly undermined.

Considering the health potential of HIV services, many in the health-care community continue to question why people wait so long to get tested and engage in HIV care. The reasons, however, are reflected in the interplay of psychosocial, culturally, and community-based determinants that steer the lives of many people who are members of populations heavily impacted by HIV.20,21 A more in-depth examination of communities disproportionately impacted by the disease—African-Americans,

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**FIGURE 1**
Continuum of Care

<table>
<thead>
<tr>
<th>Not in Care</th>
<th>Fully Engaged</th>
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<tbody>
<tr>
<td>Unaware of HIV status (not tested or never received results)</td>
<td>Entered HIV primary medical care but dropped out (lost to followup)</td>
</tr>
<tr>
<td>Aware of HIV status (not referred to care or did not keep referral)</td>
<td>In and out of HIV care or infrequent user</td>
</tr>
<tr>
<td>May be receiving other medical care but not HIV care</td>
<td>Fully engaged in HIV primary medical care</td>
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**THE IMPORTANCE OF HIV/AIDS CARE**

Retaining patients in care results in better health outcomes.

Attending all medical appointments during the first year of HIV care doubled survival rates for years afterwards regardless of baseline CD4 cell count or use of ART.

Hispanics/Latinos, Asians, Native Hawaiians/Pacific Islanders (NH/PIs), and American Indians/Alaska Natives (AI/ANs)—and the barriers and stigma they face provides a greater understanding of the complexities around engaging hard-to-reach PLWHA into care.

HIV STIGMA—MORE THAN 30 YEARS IN THE MAKING

Many PLWHA do not seek testing or care because of the stigma associated with the disease. Soon after HIV/AIDS was first described in the CDC’s Morbidity and Mortality Weekly Report (MMWR) in 1981,22 the disease became synonymous with White gay men. Sources for the first New York Times article about AIDS attributed the illness to “homosexual men [having] multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week.”23 In the same piece, James Curran, a medical doctor, said “nonhomosexuals” had no reason to worry since “no cases have been reported to date outside the homosexual community.”23

Early names for HIV/AIDS infection, such as gay cancer, gay-related immunodeficiency or GRID, gay compromise disorder, and community-acquired immune dysfunction,24–26 further stigmatized the disease, as did the declaration of official risk groups. Known as the “4H club,” these groups included Haitians, homosexuals, heroin users, and hemophiliacs. All but hemophiliacs were vilified in the press, although children infected by HIV-contaminated blood products, including Ryan White and the Ray brothers of Florida, were not spared by their local communities. Many HIV-positive children and their families left their homes in the wake of death threats and violence.27,28

These misguided notions continue to persist, even though the disease was renamed in 1982 and, soon after, diagnosed in women, children, adolescents, and heterosexual men.29–31 Caribbean and African immigrants, and men who have sex with men (MSM) in particular, continue to be blamed by many for introducing HIV/AIDS to the U.S. population, though nearly one-third of estimated AIDS diagnoses cases in 2010 were attributed to heterosexual contact, compared to 3 percent in 1985.29,32

COMMUNITIES HEAVILY IMPACTED BY HIV

To this day, HIV is often perceived as a “gay, White man’s disease,” leading many people, including members of underserved and marginalized populations—such as urban-based MSM of color—to believe they are not personally at risk. This may be the case even if they know others in their community living with HIV/AIDS. This is particularly true among youth, who can feel invincible and, if infected with HIV, are not far enough along in their disease to feel ill.33–36 The disease has changed in
SEEKING A MODEL OF CARE THAT SPECIFICALLY ADDRESSES PLWHA LIVING WITH SUBSTANCE USE DISORDERS?

Clinics and other stakeholders interested in integrating SUD treatment into HIV primary care may be interested in the IHIP training manual, curriculum, and online trainings, *Integration of Buprenorphine into HIV Primary Care Settings*, available here: www.careacttarget.org/hip.

These materials provide HIV primary care providers information and training materials necessary to integrate medication-assisted treatment (MAT) with buprenorphine into HIV primary care. They provide a detailed overview of buprenorphine within clinical settings, from the legal requirements for implementation to step-by-step procedures for prescribing and administering buprenorphine.

In terms of its geographic location. What started as primarily an urban disease quickly moved to rural pockets, particularly in the South.37,38

Ethnic and racial minorities bear the greatest HIV burden within the United States. They account for nearly 70 percent of the approximately 50,000 new HIV cases diagnosed every year; well over one-half of all PLWHA nationwide;39 and the majority of all HIV/AIDS deaths since the start of the epidemic.40 While African-Americans and Hispanics/Latinos bear the greatest burden of HIV in the country, the disease has also disproportionately impacted Asians, NH/PIs, and AI/ANs. It also continues to devastate populations that cut across these communities, including gay men/MSM and IDUs.

Perhaps most distressing is that PLWHA in these communities tend to learn their status later and progress to AIDS sooner than their White counterparts. In fact, the CDC reported in 2009 that 31 percent of Blacks, 37 percent of Hispanics/Latinos, 29 percent of AI/ANs, and 34 percent of Asians received an AIDS diagnosis within 12 months of being diagnosed with HIV.32 Engaging PLWHA in these communities into care and ART is essential to ending the AIDS epidemic.

HIV Prevention Trial Network (HPTN) 052 demonstrated that ART reduced HIV transmission to uninfected partners by 96 percent.41 ART also has been linked to decreasing rates of new HIV infection diagnoses and overall community viral load in areas with high concentrations of PLWHA and persons at high risk for HIV, such as MSM and IDUs.41,42 In addition, ART is linked to reducing HIV-related morbidity and mortality and perinatal HIV transmission,43,44 and is shown to decrease inflammation and immune activation. The latter tends to occur more often among PLWHA than their HIV-negative counterparts, and may be linked to cardiovascular and other organ damage.41

Please refer to the appendices for specific overviews concerning the impact of HIV/AIDS within African-American/Black, Latino/Hispanic, NH/PI, and AI/AN communities, as well as among women, incarcerated PLWHA, MSM and young MSM.

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**FIGURE 3**

Estimates of New HIV Infections in the United States in 2009, for Most-Affected Subpopulations

As noted previously, this manual provides insight into the outreach and engagement best practices developed across different SPNS initiatives, most notably:

- American Indian/Alaska Native Initiative
- Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color
- Targeted Peer Support Model Development for Caribbeans Living with HIV/AIDS Demonstration Project
- Demonstration and Evaluation Models that Advance HIV Service Innovation Along the United States-Mexico Border
- Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care
- Enhancing Linkages to Primary Care and Services in Jail Settings
- Enhancing Access for Women of Color Initiative.

These SPNS initiatives resulted in innovative methods to engage hard-to-reach populations into care. Highlights of approaches common to the SPNS initiatives are provided herein rather than specific detail for each initiative. Information was gleaned from interviews with, and research by, SPNS grantees and evaluators from the SPNS projects and HRSA staff. Several of these SPNS initiatives, in turn, were inspired by the CDC’s Antiretroviral Treatment and Access to Services (ARTAS) approach, which heavily emphasizes linkage to care following HIV testing, to ramp up outreach efforts.\textsuperscript{16,45–47}
The models in this manual address issues in the chart above (Figure 4), which demonstrates the iterative path PLWHA commonly take in seeking HIV care. Each PLWHA has their own set of psychosocial and economic issues, as well as personal and cultural factors, detailed in previous chapters of this manual, that dictate their readiness and ability to engage in HIV care.

The models also helped patients overcome “disabling factors” that prevent them from accessing care. Clinics that most successfully engaged hard-to-reach PLWHA developed approaches that expanded upon their current activities, rather than started completely from scratch. Below, the hallmarks of these successful HIV care models are outlined.

HALLMARKS OF SUCCESSFUL MODELS OF HIV CARE

Client-Level Features

1. Receive intensive services and support geared to their specific needs. Constant engagement by both clinical and nonclinical staff, particularly within the first few months of diagnosis, and engagement in care are key to positive health outcomes.

2. Trust of the medical provider, who assesses client readiness in care and provides health education as necessary.

3. Are linked and engaged in care through culturally and linguistically competent mechanisms.

Provider/Clinic and System Features

1. Create strong partnerships with other providers.

2. Develop and maintain diverse and highly trained culturally and linguistically competent clinicians and staff to meet the needs of vulnerable PLWHA.

3. Maintain an accessible, discrete location with nonclinical waiting and office areas, accommodating hours of operations, and flexible scheduling systems to meet the needs of PLWHA.

4. Provide active linkages and referrals, where patients are personally guided into systems of care, rather than given a list of names, addresses, and appointment dates. This may include intensive followup to ensure that patients are fully engaged in care.

5. Maintain meticulous records and quality improvement standards to ensure that patients receive the best medical and ancillary care services possible. Incorporate modern data software-tracking and information-sharing systems as allowed by their current budget.

6. Provide ongoing refresher trainings and put written standard operating procedures, policies, and practices in place to facilitate access to and ongoing engagement in care for PLWHA.


Table 1
Definitions of Common Terms and Models of Care

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<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Adherence to ART</td>
<td>Adherence means taking medication regularly, as prescribed. Antiretroviral therapy (ART) adherence refers to patients who take their HIV medications as instructed nearly 100 percent of the time. Adherence is essential to preventing drug resistance, significantly lowering or achieving undetectable viral loads, and subsequently improving PLWHA health outcomes and reducing transmission risk.</td>
</tr>
<tr>
<td>Community Viral Load</td>
<td>The average of all viral loads of a specific community of PLWHA results in a measurement called the “community viral load” (CVL). The CVLs of different populations can be compared and disparities identified and addressed. Lowering a community’s CVL requires PLWHA to become engaged in care and ART-adherent, since this means they are likely to have low or undetectable viral loads and less likely to transmit the virus to others.</td>
</tr>
<tr>
<td>Engagement in Care</td>
<td>Engagement refers to an ongoing series of interactions between PLWHA and a continuum of care with a variety of providers, including outreach workers, case managers, clinic staff, medical personnel, counselors, ancillary service providers, etc. Clinically, patients are considered engaged in care if they have had at least 1 visit in each 6-month period with a single HIV care provider within a 12-month period.</td>
</tr>
<tr>
<td>Full Engagement in Care</td>
<td>Full engagement in care occurs when PLWHA have a complete, regular, ongoing involvement in primary medical care. Similar to “engagement in care,” it is clinically defined as 2 visits within a 12-month period that are at least 3 months apart.</td>
</tr>
<tr>
<td>Health Service Navigator</td>
<td>Health Service Navigators (HSNs) are staff members trained to provide intensive care management for PLWHA entering care and/or may be accessing services from partnering providers. HSNs may conduct care assessments and develop action plans to help their clients identify their care goals and understand how they can reach them.</td>
</tr>
<tr>
<td>Intensive Case Management</td>
<td>Intensive case management involves coordination of medical, mental health, and other services in the context of frequent meetings and check-ins, often for a set period of time.</td>
</tr>
<tr>
<td>Linkage to Care</td>
<td>Linkage involves the initial connections and entry points of care after HIV testing and disclosure. Linkage may include referral by a case manager to a treatment program for substance use disorders (SUDs) as well as medical and mental health care. In addition, persons who test negative for HIV may be linked to a peer counselor for additional guidance around HIV prevention.</td>
</tr>
<tr>
<td>Lost to Care</td>
<td>Patients who have had at least 1 visit in the last 2 years with a provider, but have not been to the facility within the last 12 months.</td>
</tr>
<tr>
<td>Outreach</td>
<td>Outreach is a series of singular events geared to finding people who are at risk for or living with HIV, to offer education and to link people to HIV testing and care. These events can include health fairs and encounters outside entertainment venues. They generally do not refer to ongoing activities that retain people into care, such as appointment reminders.</td>
</tr>
<tr>
<td>Peer/Near-Peer</td>
<td>Peers and near-peers are outreach workers or counselors who encourage people at risk for HIV to get tested, and work to keep PLWHA engaged in HIV prevention, care, and treatment. Often peers and near-peers are from the same ethnic and racial background and the same general age as the clients they serve.</td>
</tr>
<tr>
<td>Retention in Care</td>
<td>Describes ongoing, full engagement of PLWHA in care over time. Sometimes used synonymously with “full engagement in care.”</td>
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<td>Reengagement</td>
<td>Reengagement refers to patients who return to care after having fallen out of care in the past.</td>
</tr>
<tr>
<td>Sporadic Care</td>
<td>Clinically, sporadic care refers to patients who have seen an HIV provider no more than 1 time in a 12-month period. These patients would be considered unstable in care.</td>
</tr>
<tr>
<td>Time-Limited</td>
<td>Time-limited interventions take place during a set time period. For instance, a new, reengaging, or unstable patient may receive intensive case management until he/she is stable and able to better navigate their care independently.</td>
</tr>
<tr>
<td>Unstable in Care</td>
<td>Patients who are unstable in care—indicated through factors such as missed appointments, not being adherent to ART, and SUDs—are considered at risk and on the verge of falling out of care.</td>
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### Models of Care

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<td>Traditional Street/Social Outreach Model</td>
<td>This outreach model often involves having peers engage in outreach with at-risk persons in their communities, often in public arenas, such as public events and entertainment venues.</td>
</tr>
<tr>
<td>Motivational Interviewing Model</td>
<td>Rather than a singular outreach event, motivational interviewing (MI) is delivered by peers and near-peers, who are trained to provide culturally and linguistically competent counseling. MI is designed to help patients align their behaviors with their treatment goals so they become engaged and retained in care.</td>
</tr>
<tr>
<td>Health System Navigation/Retention in Care Coordination</td>
<td>HSNs work with PLWHA clients to support engagement in care with partnering providers. They conduct assessments, codevelop action plans with PLWHA, and coordinate care across providers.</td>
</tr>
<tr>
<td>HIV Interventions in Jails</td>
<td>This model leverages the jail setting (and related correctional institutions such as parole offices) to identify and engage PLWHA into care. The uniqueness of HIV care in jail settings involves its own model, which in part is a hybrid of several others in this training manual.</td>
</tr>
<tr>
<td>In-reach (reconnecting past patients lost to care)</td>
<td>Providers work with partnering agencies and use their databases as a resource to identify PLWHA who have fallen out of care, contact them, and help them to reengage in care.</td>
</tr>
<tr>
<td>Social Marketing Campaigns/Social Networking Channels</td>
<td>Social marketing uses commercial advertising techniques to “sell” HIV prevention, testing, treatment, and care through messages targeted to specific populations. Television and radio advertisements and promotional materials are often repurposed and circulated online through social networks, such as YouTube, Facebook, and Twitter.</td>
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SPNS initiatives have tested numerous models of care over the past 20 years. Several of the most successful interventions for engaging hard-to-reach populations are described below.

**TRADITIONAL STREET/SOCIAL OUTREACH**

Traditional street/social outreach is a common model used to reach vulnerable PLWHA and link them with information about HIV prevention, testing, treatment, and care. In some instances, this may involve providing the actual testing—most often, oral swab testing for immediate results—and hands-on linkages to care. The provider leverages peers and near-peers to approach and work with the targeted population. These are often dedicated volunteers and/or entry-level personnel who are either the same or close in age to the target population and share their ethnic, racial, cultural, and linguistic background. They tend to be able to develop a more immediate rapport with the target population. Most are trained nonclinical staff members and volunteers who may or may not hold other positions within the clinic. Some SPNS providers leverage clients from the target population who had successfully engaged in care through their clinic.48

Outreach workers serve as a link between the community and the clinic, and play an integral role in ensuring that vulnerable PLWHA in those target areas engage in care. The success of this approach rests on the outreach workers themselves. It is critical that they have a caring, nonjudgmental approach and attitude toward potential clients, since many have mental health issues, may be injecting drugs or using other substances, and may be engaged in sex work.

*How It Works and Where.* Staff are “stationed” in areas and communities frequented by the target population, with outreach workers positioned with a health-care van or exhibit booth. Outreach workers also may approach the target population on public transportation or at local service/entertainment venues, including popular nightclubs, bars, and restaurants. These venues and events may be associated with HIV and/or general health, as well as cultural, sexual, and gender identities.49

Encounters with the public may include distribution of condoms and harm-reduction materials (as allowed), and/or educational materials. These encounters are often brief and singular.

*Opportunities and Benefits.* This approach benefits from its intimacy with—and ready recognition as a medical intervention by—the target populations. The intent of outreach work is to capture the audience’s attention, encourage them to practice safer sex, get tested for HIV, and engage in care as necessary. Since outreach workers usually have time-limited rather than ongoing
interactions with people, less training is required for this position than for case managers and health system navigators (HSNs). Outreach workers often offer rapid testing at offsite venues. Those identified as PLWHA are connected directly with a case manager onsite who provides counseling and sometimes chaperones them to another location for followup testing and linkage to HIV/AIDS care.

Resources and Other Logistical Requirements/Limitations. Staff buy-in must be secured through training and, if possible, focus groups. It often proves beneficial to have consumer voices, such as those on the local Ryan White Planning Council, at events as well.

Funding needs for this model can vary, depending on the intensity of the outreach effort. Resources may be needed to train outreach workers, as well as secure necessary solicitation permits. The purchase, rental, licensing, and maintaining of a health van or other vehicle may need to be considered. Educational materials—such as flyers, bleach kits, and condoms—for those contacted through the outreach endeavors may need to be purchased as well.

While this model can be implemented with limited training and in nearly any location, there are some limitations to traditional social/street outreach. Some SPNS sites literally found it difficult to find their target

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**FIGURE 5**

Traditional Street/Social Outreach Logic Model

Traditional Street/Social Outreach → PLWA

- **Positive Result**
  - HIV Testing
  - Eligible for Case Management
  - Ineligible for Case Management

- **Case Management Assessment**
- **Primary Medical Care**
- **Peer Advocacy**

- Reinforcing and Interrelated Services
  - ADAP
  - Mental Health
  - Support Services
  - Social Services
  - Substance Use Treatment
  - Dental Care
  - ART Adherence Assistance
  - Individual Counseling and Support Groups
  - Health Education
  - Legal, Housing, Transportation, Food, Child-Care Assistance

Negative Result → Education
population, although they did take the opportunity to provide HIV and health education to other vulnerable groups. Staff turnover tends to be high since the work is often more seasonal and geared to younger people with limited work experience. Though data collection also can prove difficult outside of an office setting, recent advances in notebook computing, data-tracking software, and Internet connectivity promise to make record-keeping more streamlined and secure.

Concerns about privacy also make connecting with target populations, such as migrant workers, Hispanics/Latinos, and young men who have sex with men (YMSM) of color, challenging, since they may be reticent about being approached by HIV outreach workers due to fears of being identified as HIV-positive in their local communities. SPNS sites addressed these concerns by framing their efforts as overall health and wellness outreach, including a menu of free primary care services, such as referrals for mental health care and treatment for SUD/addiction, sexually transmitted diseases (STDs), and tuberculosis, as well as women’s health-care services. This approach transforms van-based outreach into a health-care resource for the community. Instead of “the AIDS van,” it is a vehicle for providing health care, making it possible for PLWHA seeking care to discreetly approach and ask for assistance without fear of disclosing their status.

This is an idealized vision of the outreach model, and presupposes that PLWHA contacted by outreach workers will follow through and seek care. The one-way arrow in the model (Figure 5 on page 13) indicates the limited depth of the traditional street/social outreach approach. If PLWHA fail to follow through with care, there is a possibility they could be lost to the clinic. Even if they provide a telephone number and/or address, the populations targeted through this model tend to be more mobile, and their contact information may change frequently.

**MOTIVATIONAL INTERVIEWING**

MI is grounded in the transtheoretical model (TTM) of change, and explains or predicts a person’s success or failure in making a proposed behavior change.\(^{50,51}\) In practice, it involves culturally and linguistically competent counseling to create a welcoming environment for PLWHA and encourage them to get tested and engage in care. MI is more flexible than traditional outreach, since it can be provided within a clinic or offsite. When outreach workers encounter PLWHA, they use MI to encourage participants to examine their own motivation to know their HIV status,\(^{52}\) thereby helping them feel more involved in their testing, treatment, and care experiences.\(^{53}\)

**How it Works and Where.** MI generally takes place in a private office, rather than a health van or offsite location. It often requires longer, more intense interaction than other models, since patients are guided through a number of steps geared to helping them identify discrepancies in their health goals and current behaviors, and to devise plans to make positive changes. The stages of change through MI generally involve:

- **Precontemplation:** This stage occurs at the start of the conversation, when most PLWHA have not yet acknowledged there is a problem behavior that needs to be changed or addressed. For instance, the MI counselor may ask PLWHA if they think they need to address their HIV, and how they might accomplish that under their current circumstances.
- **Contemplation:** At this stage of interaction, the MI counselor has helped the person acknowledge there is a problem, even if he/she may not be ready or even want to make a change.
- **Preparation/Determination:** At this point in the conversation, the MI counselor helps the patient get ready to change, often asking more probing questions, such as: “You say you are concerned about your health, but you are not using condoms. Why is that? How does that help you stay healthy?”
- **Action/Willpower:** At this stage, the MI counselor has helped the person feel empowered to outline and start engaging in changing behavior. This might involve making an appointment for medical care.
- **Maintenance or Relapse:** MI counselors may check in periodically with PLWHA to see if they have maintained their behavior change and are still in care. Those who were unable to maintain change—as evidenced by falling out of care or returning to past high-risk behaviors—may benefit from intensive case management and participating again in the MI process.\(^{54,55}\)

Though time-limited, MI is not a singular encounter, but meant to be part of a relationship that helps PLWHA identify their goals and develop ongoing relationships with clinicians and staff.
MI is often followed up with intensive case engagement such as providing transportation to appointments, and consistent followup via telephone calls, texting, e-mails, and other communications mechanisms. In addition to reminding PLWHA to take their medications and go to appointments, MI personnel discuss the issues their clients may be facing, such as FISI and treatment adherence. When needed, patients are given referrals for additional support services, such as health and medication education resources, nutritional support, housing, mental health, and SUD treatment. In these exchanges, additional incentives or contingencies, such as gift cards and clothing, may be provided to PLWHA to encourage them to remain in care.

Figure 7 (page 16) is similar to the traditional street/social outreach approach; however, in the case of MI, the HIV-positive person and MI staff person are engaged in an ongoing dialog. Their relationship, though time-limited (depending on the facility), is far more extensive than that with outreach workers and is meant to ensure that patients reach full engagement in care.

Resources and Logistical Requirements/Limitations. MI requires specialized counselor training, and can be an ongoing expenditure for clinics that incorporate MI into their practice. Traditional outreach staff members are sometimes volunteers or employed in a limited fashion. MI personnel often are more permanent staff persons, and are required to undergo extensive training and instruction before being certified to work with clients. Tapes of MI sessions, both practice and real-time, are reviewed by a third party to ensure the integrity of the interviewer’s technique. (For more information on MI techniques and approaches, visit the Motivational Interviewing Web site at www.motivationalinterviewing.org, and also review the resources provided in Section 8, “Continuing the Conversation.”)

To mitigate training costs, several SPNS sites recruited culturally and linguistically competent staff that clients seemed to trust, even if they were not peers. One location reported training a case manager in MI after noting her popularity with their target population. Though much older than the clients, she understood their needs and backgrounds, and the stigma they faced at home and in their communities due to their HIV status and sexual orientation.

The returns on investment are always worthwhile; MI often results in longtime engagement of PLWHA in care, with successful reduction in or achievement of...
undetectable HIV viral loads. SPNS participants report that PLWHA who became engaged and retained in care through MI often refer their peers to the clinic—an unexpected, though welcomed, spillover effect. This model proved particularly successful in reaching out to younger PLWHA who need support engaging HIV testing and care. The extensive training and sensitivity puts PLWHA at ease. MI requires a quiet meeting space, such as an office or health van, with no one else present. A drawback to MI is that it can be time-consuming, both in terms of execution and training.

**HEALTH SYSTEM NAVIGATION/ENHANCED CASE MANAGEMENT**

Most clinics are unable to provide all of the primary care and ancillary services that PLWHA need, requiring them to partner with other providers to create a complete spectrum of care. Keeping appointments at different agencies can be overwhelming, particularly for PLWHA who are new to, or reengaging, in care. These patients are often assigned an HSN, a nonclinical staff person whose skill sets combine those of case managers,
outreach workers, and/or peer advocates. This service “connector” staff person is sometimes called a service worker or peer advocate.

HSNs offer empathetic and caring support to PLWHA on a personal level. The approach alleviates PLWHA’s fears about linking to and engaging in care, and offers them an opportunity to learn how to navigate services across different providers. They also serve as advocates for clients, acting as a liaison between the patient’s medical providers, case managers, and other clinical staff.

Though similar in some respects to case managers, HSNs are involved with patients on a time-limited basis. Intensive guidance is provided to clients during a concentrated time period to ensure they are fully engaged—and ultimately retained—in care. Patients then take over their own routine of HIV primary care, support and social services, with HSNs following up at regular intervals, often 6 to 18 months later, depending on the needs of their clients and the resources of the partnering agencies.

This personalized or “enhanced” approach to coordinated case management has proven particularly successful with PLWHA who are currently not in care or are unstable in care, and who need extensive support. The model involves several phases:

1. The lead clinic/agency partners with one or more agencies to identify and retain PLWHA into care.
2. Unstable PLWHA are identified through a variety of means, including interviews and surveys that assess a client’s health literacy and personal situations in relation to FISI, employment, and so on.
3. Patients identified as unstable in care are assigned an HSN, who conducts care assessments designed to delineate their care goals and understands how to reach them.
4. An HSN helps patients become fully engaged and retained in care, and works to ensure that they keep appointments and fill their prescriptions. This is done through intensive clinic contacts that include, but are not limited to, personal telephone calls regarding upcoming and missed appointments, and chaperoned visits to offsite medical and social services.
support service meetings, court dates, health education classes, and so on. HSNs may help PLWHA obtain housing, connect them with medical case management, and provide other services that ensure they stay ART-adherent and retained in care.

5. Additional support may be provided to PLWHA who are experiencing challenges with remaining engaged in care. For instance, patients may be offered directly observed therapy, where HSNs and/or other staff help PLWHA take their medications, ensuring ART adherence.

How It Works and Where. The network of partnering providers, in effect, operates like a patient-centered medical home,58 where most, if not all, core medical and ancillary care services are provided under one roof, or in close proximity, ensuring that PLWHA can more readily be engaged fully and retained in care. Clinics that use HSNs to coordinate care have helped to stabilize PLWHA—in terms of their care and their personal lives—and have helped with patient self efficacy. Patients report being able to maintain ART adherence and reach undetectable HIV levels. They also are able to manage their SUDs and mental health issues more readily, which are key to remaining engaged in HIV care.59,60 Research has shown that over time, these elements have helped to significantly reduce the community viral load in local areas served by the participating clinics.61

Opportunities and Benefits. HSNs also help case managers from being overwhelmed by their often large caseloads, providing new PLWHA the more personalized care they need to keep appointments and become treatment-adherent.

Resources and Logistical Requirements/Limitations. Clinics must have the staff or the capacity to train current, or recruit new, employees to become HSNs. Some difficulty may come into play if HSNs work across agencies: This can be averted by clear, concise memoranda of understanding (MOUs) and consistent communication among partnering agencies.

This model is relatively inexpensive to implement, although HSNs can suffer from burnout due to the amount of personalized attention involved in supporting and assisting PLWHA. High turnover rates could mean ongoing training costs for agencies constantly hiring new HSNs, as well as inconsistent care for particularly vulnerable PLWHA. Other expenses might be incurred if legal counsel is sought during the creation of formal MOUs. In that instance, agencies may consider informal agreements, in which HSNs would follow their home agency’s protocol around referring clients to other agencies for care.

HIV INTERVENTIONS IN JAILS: A HYBRID APPROACH

While incarceration can interrupt PLWHA’s HIV care, jail settings also offer an opportunity to identify, engage, and reengage PLWHA in care. Agencies replicating this model, as with the HSN model, are called on to create outside partnerships—this time with their local jails. Partnerships in these instances tend to be controlled by the jails, since they are required to manage the movements and activities of inmates under their supervision—for their protection, and the safety of the staff, visitors, and the general public.

Most SPNS sites working in jails selected the facility closest to their medical offices, since the proximity often encouraged recently released PLWHA to access treatment and care. HIV testing in the jail facility is often offered during the intake process, giving prisoners who opt-in for testing some semblance of privacy in a facility that otherwise is completely open. Some SPNS sites distributed socks and underwear to all prisoners at intake, providing an additional layer of privacy to those who did opt-in for testing since no one was singled out for attention. Others offered testing during group HIV education activities, allowing people who wanted to be tested the anonymity of the group. Indeed, some PLWHA opted to be tested in order to access care, rather than disclose their status to jail staff.

How It Works and Where. Identifying PLWHA as soon as they enter the jail also afforded SPNS site staff the maximum amount of time possible with PLWHA in the facility. Time is often of the essence, since most inmates only stay in jail approximately 24 hours.62 During that time period, SPNS staff maximized their time with patients, conducting health assessments to determine if they required ancillary services beyond primary care, such as those for mental health, SUDs, and FISI.

Several SPNS projects specialized in working with the local courts to create responsible solutions for incarcerated PLWHA. For instance, staff often worked with the courts to have PLWHA with SUDs sent to an inpatient drug rehabilitation clinic upon release. Others were transferred to a monitored halfway house, where they

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received a supervised introduction to HIV services and care. Perhaps most important, patients often were given transitional care coordination in the form of a “warm exchange” upon release—a care package often containing a letter for their provider that included their HIV test results and other lab work; a packet of appropriate paperwork, such as AIDS Drug Assistance Program (ADAP) and/or Medicaid insurance applications; condoms; clothing; food; and a prescription for or supply of their medications.

**Resources and Logistical Requirements/Limitations.** The greatest challenge to replicating this model is whether a facility can create a partnership with the jail system, which has many competing concerns. Some common issues arose for community health centers and AIDS service organizations when they initiated a relationship with their local jails and began to conduct testing. The issues—and the workarounds SPNS grantees created to address them—include the following:

- Some jail administrators viewed HIV testing as a potential administrative and staffing burden. SPNS sites worked around this issue by outlining exactly what they wanted to accomplish and what staff would be onsite to ensure that everything was completed properly and there would be no additional work to burden jail staff. Sites often sent

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**FIGURE 9**

HIV Interventions in Jail Logic Model

- PLWHA Enters Jail
- Intake Process Provider Offers HIV Testing
- PLWHA Declares Status or Accepts HIV Testing
- HIV Testing
- Linkage to Care/Discharge Planning Jail Setting
- PLHWA Released from Jail
- Intensive Case Management Linkage and Engagement in HIV Care
- PLWHA Accepts Testing Later after Initial Refusal
more than one clinical staff person to the jail to enable multiple tasks to be completed simultaneously, including testing, post-testing counseling (where possible), and health assessments. Finally, staff took the lead in all testing processes, like obtaining medical records for inmates who transfer in from other correctional facilities.

- Some inmates believed that testing is not opt-out due to the coercive nature of corrections. SPNS sites worked around this issue by creating a set script and protocol to help reassure inmates of their rights.
- Staff were not given enough time to test and counsel patients. Jail settings often limit time with inmates, which can make it difficult to get results from even the fastest tests. Clear expectations on both sides about the time needed for and allotted to meetings with patients often mitigated these misunderstandings.

Sources: CDC. What is the difference between jail and prison? 2006. Available at www.cdc.gov/nchstp/od/cccwg/difference.htm.

The additional laboratory costs incurred by implementing HIV interventions in jails can often be offset via partnerships with local and State health departments, and through bulk purchasing contracts with vendors. Indeed, flexibility, dedication to safety protocol, and accommodating the partner jail are key to success in replicating this model of care. For instance, some SPNS sites opted to work outside of jails in parole offices to reach recently incarcerated PLWHA, holding general health literacy meetings followed by private appointments for testing and case management. Another site had to re-focus their target population when their project, geared to women, attracted only male PLWHA participants.

IN-REACH

Some SPNS sites conducted extensive in-reach efforts within their clinic, as well as local clinics and health departments, to reengage PLWHA lost to care. This approach was most efficient in identifying participants for intervention, particularly with hard-to-reach populations, such as YMSM and women of color. Some grantees coupled this approach with HIV testing efforts in emergency rooms, sexually transmitted disease clinics, health clinics, and other health-care settings these populations often frequent for non-HIV related services.
Special staff training is not required for this model. In general, contact with clients is initiated by a non-clinical staff person who has experience working with the clinic’s database and/or patient records and knows how to quickly identify clients who have fallen out of care. It is recommended that this staff person use a script to help guide their outreach efforts with patients. It is essential that they have a strong understanding of Health Insurance Portability and Accountability Act of 1996 (HIPAA) rules to ensure that patient confidentiality is maintained, particularly in cases where it is unclear if the contact information on file for a patient is reliable.

How it Works and Where. This process, which involves going through past records and contacting patients who have fallen out of care, requires clinics to have sound recordkeeping practices and reliable information on patients.

Reconnecting with these patients often offers them a lifeline back to care that did not seem to exist for them previously, and shows that someone cares about their well-being. Moreover, it helps lay the foundation for a trusting relationship with the provider and a foundation for care.

Resources and Logistical Requirements/Limitations. People who are recruited back into care often were still experiencing the issues that drove them away in the first place, such as FISI, poverty, under- and unemployment, and lack of insurance. Reengaged PLWHA tended to
require (at least initially) intensive case management and/or MI, during which they assessed their health care goals and steps they needed to take to become fully engaged in care. As with the other models, this intensified case management is time-limited, though it often lasted longer than in other models due to the unstable situations of many PLWHA brought back into care.

Other limitations were administrative, such as limited or out-of-date records. Clinics that worked exclusively with paper files experienced major difficulties in finding PLWHA. Providers with modern electronic medical records (EMRs) often had more success with this model.

**SPECIAL MARKETING/SOCIAL NETWORKING CAMPAIGNS**

Social marketing involves leveraging traditional marketing techniques to promote healthy behaviors. In the HIV arena, the approach is often used to encourage people, particularly in high-risk communities, to get tested for HIV, and to engage in treatment and care as necessary. PLWHA and at-risk persons referred to a clinic through these messages not only are linked to HIV care, but also receive additional educational training and resources, and are assigned to a case manager who provides access to ART, mental health care, treatment for SUDs, and other necessary support services.

Social networking refers primarily to online communications through various new media communications tools and information-sharing Web sites, including wikis, blogs, and microblogs. (For more information, visit AIDS.gov’s online tutorial, *How to Use New Media*, available at [http://aids.gov/using-new-media/](http://aids.gov/using-new-media/).

**Staffing.** This generally involves a team of clinical and nonclinical staff creating ideas through focus groups and idea sessions. These staff may also invite clients, members of the public, and consumers on local Ryan White Planning Councils to weigh in on the messaging and images used throughout the development and launch of the project.

**How It Works and Where.** Social marketing materials are aired on television, the radio, and online; they can effectively target hard-to-reach members of populations with little staff involvement. Some SPNS sites promoted their social marketing campaigns with additional materials such as posters to further raise awareness of HIV and the services they provide.

Many HIV campaigns find additional “legs” through repurposing—reposting information in abbreviated form to encourage audiences to visit the source site—on social networking sites, such as YouTube, Facebook, and Twitter. When promoted in this manner, the return on investment can be invaluable, bringing hard-to-reach populations into care—such as youth ages 13 to 29, as well as migrant/mobile, homeless, and IDU populations dependent on intermittent access to mobile technologies for their health information.

**Resources and Logistical Requirements/Limitations.** Social marketing messaging often requires a great deal of advance planning, design, and focus group testing before launch. Development and implementation can be expensive, since both often involve contracts with vendors for design, film production, and television ad space. Sites considering this approach need to assess how many people they believe will be reached by their products, and if they really believe they can enact behavior change. Moreover, today’s fast-paced media markets can make a social marketing campaign obsolete within just a few months of dissemination.

Users of social marketing techniques have to be prepared for the unexpected, which can speak to misconceptions by a clinic about who is at risk for HIV in their community. For instance, one site created a campaign targeting African-American YMSM, who they believed were heavily impacted by HIV in their area. Instead, they primarily received inquiries from Hispanic YMSM, who were not a focus population in their original model. What did they learn? Was that a bad thing? Why did another population respond? Providers may find it helpful to do a test pilot of their social marketing campaign first and then roll it out to broad audiences.

Evaluating the impact of social marketing campaigns can be challenging. It is all but impossible for small clinics to track the populations that have seen their materials and subsequently changed their behavior. The best workaround is to conduct surveys of staff, clients, and the greater community during and after the production process. This feedback should provide some information about who has encountered the campaign, and where they encountered it (such as online, on the street, in the clinic, etc.), their thoughts about its appropriateness and effectiveness, and whether they believe it would generate behavior change among their peers and/or other groups. It also may be helpful to ask what suggestions and comments, if any, the respondent has regarding the social
marketing campaign’s taglines, messaging mediums, and materials, as appropriate. (For more information, refer to the Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care Curriculum.)

A note about social networking and models of care: The power of social networking to disseminate HIV information cannot be denied. Online chat rooms are often frequented by MSM and YMSM of color to find partners. Yet initiatives seeking to send out messages to these populations, particularly youth living with and heavily impacted by HIV, have been uneven. Many vulnerable PLWHA, and particularly young PLWHA, have little access to smartphones and other technology due to limited finances.

While most social networking sites are free to use, successful implementation of a Twitter account and a Facebook fan page for a business can be time consuming for staff who need to post and moderate conversations. Some social networking sites require special back-end coding for them to function in a professional work environment. Text messaging is often considered an option as well as to reach PLWHA out of care, but it continues to be extremely expensive.

Online and global positioning system (GPS) chat rooms and social networks have developed dramatically over the past 5 years. One SPNS site was able to leverage these platforms to conduct an online survey of YMSM with the assistance of The George Washington University (GWU) School of Public Health and Health Services’ Youth Evaluation Services (YES) Center, while others used peers to disseminate health messages and invite people to ask health questions in various MSM chat rooms geared to recruiting sexual partners (i.e., online hookups). Unfortunately, many SPNS demonstration sites found social networking sites difficult for outreach purposes. Most users continue to be reluctant to interact with outreach workers in online arenas due to concerns about their privacy.63,64

Some online outreach can create challenges to monitoring staff members’ interactions with patients. This may be especially true when working with outreach workers who are youth themselves. While younger employees may have great facility with the technology and the population with whom they are working, they might require more supervision than other, more experienced personnel.
Before taking action to replicate and implement one or more of the models of care described in this manual to engage hard-to-reach populations into care, providers are asked to review the following list of issues and concerns:

- **What are the agency’s clinical measures and how does it define being engaged in HIV care?** Are these different from those used by their colleagues at other local agencies? Are they consistent with those set forth by HRSA? Are their activities aligned with the goals of the NHAS?

- **Self-reporting.** Providers may need to question how much they can trust self-reports regarding HIV care reported by clients. Some clients may define “being in care” as visiting a doctor several years before, while others would consider themselves “out of care” in that situation.

- **Data disconnect.** HIV providers often collect data differently. Some still use paper records, while others create unique EMRs for each patient that can be updated through secure online portals. Relatively few patients have the ability to share patient information online due to limitations on their electronic data infrastructures and concerns for client privacy. For these reasons, clients may seek care from different clinics without the providers’ knowledge.

- **Readiness and health status.** Research suggests that regardless of the intervention, the success of PLWHA in care depends in large part on whether or not they are already ill, and if they are willing to engage in HIV care.

- **Provider relationships and adaptability.** Is your agency ready to engage in new approaches to care? If you work with partners, are you able to accommodate their requests? If you do not offer services, can you refer clients to colocated or nearby ancillary care and support services, such as transportation, dental care, and mental health?

- **Skill sets:** Does your staff have the training necessary to engage in new approaches to care? Does your site have the capacity to train staff? Does the model you are selecting really fit the needs of your clients?

- **Are you really able to reach the population(s) you wish to target?** If you and your staff find you are unable to engage your original target population, do you have a contingency plan?
• **Is your agency ready to receive vulnerable PLWHA?** Is it in a discrete location? Is the facility inviting and the staff linguistically and culturally competent? Are you able to secure patient privacy in the waiting room by conducting universal screenings for stigmatizing conditions, such as HIV, mental illness, and SUDs? Does your agency’s workflow allow it to be responsive to patients’ needs and ensure shorter wait times and longer visits with providers?

• **Do you have the infrastructure to track patients and easily update their EMRs?** Is it set up to flag clinicians when appointments, blood work, and tests are required? Can it track patients across inpatient/outpatient settings, agencies, and States/borders to avoid duplicating services and losing them to care?

• **Do you listen to your patients?** Does your clinic incorporate input from PLWHA representatives on HIV Planning Councils and other public bodies?
CONCLUSION

For over 2 decades, HRSA’s vision and leadership has helped drive the success of the Ryan White HIV/AIDS Program, which has engaged hundreds of thousands of PLWHA into care, saving countless lives. HRSA’s work aligns neatly with the goals of the NHAS, particularly the SPNS program, which has developed numerous innovative approaches for identifying and engaging hard-to-reach PLWHA into care.

The best of these models, distilled in this manual, have been proven to help PLWHA overcome their personal, community-based, and cultural barriers to care, dramatically decreasing their viral load or achieving viral suppression, as well as dramatically reducing HIV transmission to others. PLWHA in care also benefit from health literacy and education programs, and wraparound services, many of which are geared to patients’ families, as well as to PLWHA themselves.

The SPNS models of care have helped to bring the Ryan White HIV/AIDS Program’s holistic approach to care to PLWHA who otherwise would not be able to access services. These approaches to care were never meant to exist in a vacuum, but to be replicated and adapted by providers nationwide serving vulnerable populations.

START REPLICATING THESE MODELS NOW

IHIP’s Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care Curriculum provides clinics and other stakeholders the training and guidance to assist with replication of the models of care discussed in this training manual.

The curriculum features a series of modules with:

- PowerPoint presentations that include detailed information to help presenters guide discussion and followup.
- Interactive activities to foster ideas and help implement the model of care.
- Extensive handouts, information sheets, templates, and other resources that can be adapted to the needs of one’s agency.
These appendices are population-specific and highlight the particular challenges associated with delivering care to various high-risk groups, and what issues providers should be aware of as they target and tailor their approaches. All of the populations discussed in the appendices section have been targeted through the SPNS initiatives mentioned at the beginning of this training manual.

**APPENDIX A: AFRICAN-AMERICANS/BLACKS**

HIV/AIDS has disproportionately impacted Black women, youth, and gay and bisexual men since the start of the epidemic. To put this in perspective:

- African-Americans represent 14 percent of the United States population, but accounted for nearly one-half of all PLWHA in the United States in 2010.

*Different data sources use different terms for this population. For the purposes of this training manual, the terms African-American and Black are used interchangeably to refer to all people of African descent in the United States, its territories, and possessions.

- From 2007 to 2010, approximately 44 percent of all new HIV infections occurred among African-Americans.

- The AIDS rate for African-Americans is 10 times that of Whites, and the lifetime risk of HIV infection is far greater among Blacks than any other ethnic group.

HIV in Black communities is fueled, in part, by a variety of economic determinants and health disparities:

- In 2011, African-Americans accounted for 27 percent of people in the United States living at or below the Federal poverty line, and over one-fifth

†Unless otherwise noted, HIV estimates and diagnoses are gleaned from data provided by 46 U.S. States (Hawaii, Maryland, Massachusetts, and Vermont are not included) and 5 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands). U.S. dependent areas, however, are not included in reference to HIV among specific racial and ethnic groups, since the U.S. Census Bureau does not collect demographic information from all dependent areas. AIDS surveillance data are based on reports submitted by all 50 States, the District of Columbia, and 6 U.S. dependent areas (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, Republic of Palau, and the U.S. Virgin Islands.)
of all Blacks in the country reported not having health insurance.\textsuperscript{69}

- This has resulted in high rates of FISI among African-Americans, who account for a disproportionate number—47 percent—of the country’s homeless population.\textsuperscript{70}
- High rates of STDs, heart disease, and type 2 diabetes also undermine health outcomes of African-Americans, and can complicate HIV/AIDS treatment.\textsuperscript{71}
- The rate of AIDS among prison and jail inmates—who are disproportionately African-American—is estimated to be about 2.4 times greater than that among the general population.\textsuperscript{72}

African-American women have born the greatest burden of HIV among all females living with the disease.\textsuperscript{32,73}

- In 2010, 88 percent of new HIV infections among Black women were attributed to high-risk heterosexual contact, which encompasses all unprotected heterosexual activity, including survival sex and sex work.\textsuperscript{32}
- Higher incarceration rates within Black communities leads to a loss of available men, which can disrupt social networks and may lead to risky behavior.
- Because African-American women are less likely than other women to date men outside their racial/ethnic group, the higher rates of HIV infection among African-American men have important implications for African-American women’s HIV risk, particularly as the majority of infections are a result of high-risk heterosexual sex.\textsuperscript{74}

Black men represented 70 percent of estimated new infections among African-Americans in 2010, with an infection rate approximately 6 times higher than that of White men and over 15 times that of White women.\textsuperscript{74} Nearly three-quarters of these infections resulted from male-to-male contact.\textsuperscript{76}

Fears of being “outed” as HIV-positive—and, by extension, engagement in stigmatized sexual activity—presents a powerful barrier to seeking HIV prevention, testing, treatment, and care in African-American communities. This is particularly true for Black MSM and young Black MSM.\textsuperscript{77} They face real and perceived risks of rejection by their family and friends, and often leave home at an early age.

- Young Black MSM are vulnerable to homelessness and earlier sexual debut than other youth, and often depend on older Black MSM partners for housing, food, and other resources to survive.\textsuperscript{78}
- Young Black MSM make up the majority of African-American teenagers living with HIV—who together account for only 17 percent of the U.S. population ages 13 to 19, but represent 70 percent of all new AIDS diagnoses in this age group.\textsuperscript{65}
- Young Black MSM ages 13 to 29 experienced a 48-percent increase in HIV infections from 2006 to 2009, and accounted for 60 percent of new HIV cases among all Black MSM during this time period.\textsuperscript{68}
- This spike reflects, in part, this group’s inexperience negotiating condom use, particularly with older partners, who they may fear will cut off their support. Many older Black men were infected through similar relationships in their youth, and in turn are transmitting HIV to their younger partners, helping to perpetuate HIV across multiple generations of Black MSM.\textsuperscript{79}

\textbf{APPENDIX B: HISPANICS/LATINOS\textsuperscript{‡}}

Hispanics/Latinos represent the largest and fastest-growing minority group in the country,\textsuperscript{80} accounting for 16 percent of the U.S. population in 2010—and over 21 percent of AIDS diagnoses.\textsuperscript{81}

- Hispanic/Latino men living with HIV accounted for nearly 81 percent of estimated AIDS cases among Hispanics/Latinos in 2010.
- Most Hispanic/Latino men who contracted HIV did so through male-to-male sexual contact, followed by IDU and high-risk heterosexual contact.\textsuperscript{82}

\begin{footnotesize}
\textsuperscript{‡}For the purposes of this training manual, Hispanic/Latino refers to all Hispanic populations in the United States, its territories, and possessions. Hispanic/Latino populations can represent any racial and ethnic group.
\end{footnotesize}
• High-risk heterosexual contact accounted for 77 percent of estimated AIDS diagnoses among Latina women in the United States and 6 dependent areas in 2010.82

Health outcomes for Hispanics/Latinos living with HIV/AIDS are undermined by overall lack of educational attainment, high rates of poverty, rising unemployment, language and cultural differences, immigration status issues, and lack of health insurance.83,84

• In 2010, 27 percent of Hispanics/Latinos lived in poverty, compared to the nationwide average of 15 percent.69
• Nearly 31 percent of all Hispanics/Latinos—the largest of any racial and ethnic group—were uninsured in 2010, compared to 11.7 percent of non-Hispanic Whites.69
• In 2010, only an estimated 63 percent of Hispanics/Latinos ages 25 and older had graduated from high school, compared to African-Americans, Asians, and non-Hispanic Whites who all have graduation rates in excess of 80 percent.85
• In addition, Hispanics/Latinos, particularly Hispanic/Latino men, experienced disproportionately high rates of incarceration, which further exposed them to HIV coinfections such as hepatitis and fueled HIV in their communities.

Providing care for and increasing awareness of HIV/AIDS among Hispanics/Latinos is complicated. Behavioral risk factors for HIV infection among Hispanics/Latinos can differ based on country of birth,86 and are further complicated among highly mobile subgroups fearing deportation and living in geographic isolation and poverty with limited access to culturally sensitive, high-quality health care.87–89 Indeed, research suggests that, depending on their personal circumstances and education levels, some Hispanics/Latinos may be unaware of HIV risks or exactly how it is transmitted. One ethnographic study of Hispanic/Latino men revealed beliefs that over-the-counter drugs from Spanish-language grocery stores could cure HIV.90 Cultural attitudes such as machismo—an exaggerated sense of masculinity commonly found in Hispanic/Latino communities, characterized by sexual prowess, dominance, and aggression—can encourage the acquisition of numerous sexual partners and denial of MSM behavior, undermining safe-sex practices.91

APPENDIX C:
ASIANS AND NATIVE HAWAIIANS/ PACIFIC ISLANDERS

Asians and Native Hawaiians or Other Pacific Islanders (NH/PIs) (which, until recently, were considered one group called Asian and Pacific Islanders or A/PIs) include a heterogeneous and diverse collection of approximately 50 ethnic subgroups that speak more than 100 languages, and have their origins in the Pacific, and North, South, and Southeastern Asia.92

In 2010, NH/PIs ranked fourth in number of estimated AIDS diagnoses in the United States, after African-Americans, Hispanics/Latinos, and multiple races.32 Of particular concern is the heavy impact of HIV among NH/PI MSM.

• Of the estimated HIV diagnoses among Asian men in 2010, 86 percent contracted the virus through male-to-male sexual contact.93
• Asians and NH/PIs can experience difficulty accessing care due to language and cultural barriers, as well as fears of deportation. These issues may make Western health-care facilities intimidating and communication with clinicians almost impossible.94–96
• Approximately 1 in 5 nonelderly Asians and NH/PIs lacks health insurance, inhibiting their ability to access care.97

Although rates of many diseases, including HIV/AIDS, are lower among Asians and NH/PIs than other racial and ethnic groups, they are more likely to have HIV coinfections and morbidities, including tuberculosis, hepatitis B, and certain cancers. In some geographic regions, such as San Francisco, rates of HIV/AIDS has spiked among Asians and NH/PI groups, particularly YMSM.98

APPENDIX D:
NATIVE AMERICANS/ALASKA NATIVES

American Indians/Alaska Natives (AI/ANs) represent less than 1 percent of the U.S. population—and include hundreds of diverse tribes and cultures—but have an AIDS rate 40 percent higher than Whites.68,99 “They also are more likely to die of the disease than most other racial and ethnic groups.”100
• Of the estimated HIV diagnoses among AI/AN men in 2010, 73 percent contracted the virus through male-to-male sexual contact.  
• Approximately 75 percent of estimated HIV diagnoses among AI/AN women were attributed to high-risk heterosexual contact in 2010.  
• Accessing care is often complicated for AI/ANs. Indian Health Service (IHS) providers tend to be located on rural tribal lands, although over two-thirds of Native peoples live in urban areas. Most are poor and uninsured.

Native peoples living on the reservation are closer to IHS providers, but still experience barriers around cultural differences, geographic isolation, poverty, fears of unwanted disclosure, and frequent relocation. All AI/ANs experience disproportionately high rates of HIV comorbidities and coinfections, such as viral hepatitis, tuberculosis, pneumonia, influenza, depression, type 2 diabetes, and heart disease, as well as suicide, accidental deaths, mental health issues, intimate partner violence, alcoholism, and SUDs.

APPENDIX E: WOMEN

HIV care also can run counter to many cultural norms in communities hard hit by HIV, especially since it is so closely associated with same-sex behavior and often involves mental health care and treatment for SUDs that are equally stigmatized in communities of color. Women, and women of color in particular tend to perceive themselves at lowered risk for HIV infection than single women. Initiating safer sex practices later in a relationship often proves difficult. Not using condoms is an expression of deep trust; men of color often construe any suggestion of their use to be an admission of guilt or distrust. The latter, in particular, can place them at risk for intimate partner violence and disgrace in their families and communities. This is particularly true for women with histories of childhood sexual abuse, SUDs, and post-traumatic stress disorder.

Many women feel pressured to obtain HIV prevention, treatment, and care in secret due to these cultural norms and fears. Latina women often defer HIV care altogether, in part because of marianismo, which involves female submission to husbands and other male family members in Hispanic/Latino communities. It can severely limit their freedom of movement, making access to HIV testing, treatment, and care difficult. An HIV-positive test result is often devastating for Hispanic/Latina women on many levels. Although Hispanic/Latino notions of machismo encourage Hispanic/Latino men to have multiple female sex partners and deny any same-sex attraction or activity, it is their wives—most of whom are monogamous—who will be blamed if either partner tests positive for HIV.

Similar cultural norms are found in some African-American communities, where the idea of “collective responsibility” defines women as caretakers who must put the needs of their children, husbands, and extended family before their own. Women of color, many of whom experience high rates of depression and stress, also may feel pressured to maintain a relationship at any cost, since they depend upon their partners for economic support. Some Black women will maintain a partner rather than attempt to find a new one in the ever-decreasing pool of available African-American men due to higher rates of mortality and incarceration among Black males than in other ethnic groups, especially in areas of lower socioeconomic status.

Considering their familial responsibilities, fears of rejection and violence, and economic instability, it is not surprising that many female PLWHA often miss appointments—as do members of other marginalized groups, including the uninsured, minority men, MSM, and youth. These issues often play a role in Hispanic/Latino and Black women being linked to care and prescribed ART later than their White counterparts. Without intervention, these women PLWHA are at considerable risk for progressing to AIDS, which can severely undermine their quality of life, overall health, and, ultimately, their life expectancy.

APPENDIX F: INCARCERATED PLWHA

Incarceration is one of the complex issues facing the HIV community, since it represents both a barrier to, and an opportunity for, engagement in care. Entering a jail or prison takes patients away from their regular care regimen, yet these facilities offer providers an opportunity to identify HIV-positive persons unaware of their
status and engage them, along with PLWHA currently out of care, into health education, ART, and other treatment and care services.

The rate of AIDS within incarcerated populations is estimated to be about 2.4 times higher than that among the general population. Incarcerated individuals, particularly those who have experienced homelessness and/or engaged in substance use, often are unaware of their HIV status, and may be more susceptible to coinfections, such as tuberculosis and hepatitis C. Inmates often are wary of being tested in prison due to stigma associated with HIV and the possibility that their status may be disclosed to the rest of the prison population due to the general lack of privacy. Communities disproportionately affected by HIV/AIDS are also overrepresented within these institutions. More than one-half of all incarcerated persons are African-American and Hispanic/Latino men and women.

Of all incarcerated ethnic and racial minorities, African-Americans tend to enter prisons and jails in the poorest health, and prove particularly vulnerable to falling out of care upon release. Compared to incarcerated PLWHA from other racial and ethnic groups, Black HIV-positive men were more likely to be MSM, and experience intense FISI, mental illness, and SUDs. This group of PLWHA, particularly Black PLWHA men, often are more likely to have longer lifetime incarceration histories, be charged with violent offenses, and have higher rates of recidivism.

Reasons for incarceration differ along gender lines, however, with most women incarcerated for sex work and SUDs. Men, however, are incarcerated for numerous reasons, many of them related to violence and parole violations. The needs of male and female PLWHA, while often different, are not necessary more intense for one gender or the other upon leaving incarceration. Both experience additional difficulties with engaging in care if returning to a previous life situation that led to their arrest in the first place, and most often continued engagement in illegal drug use and sex work. Those not engaged in strong health-care programs focused on SUDs and mental health care experience significantly higher rates of recidivism than other formerly incarcerated PLWHA.

**APPENDIX G: MEN WHO HAVE SEX WITH MEN**

As noted previously, homophobia has played an integral role in stigmatizing HIV/AIDS and has created substantial barriers to HIV prevention, testing, treatment, and care among MSM, and YMSM in particular. The impact of HIV among gay men and MSM has been devastating. Although they represent only 4 percent of the male population in the United States ages 13 and older, the CDC reported that they accounted for 61 percent of new HIV infections in 2009.

YMSM ages 13 to 29 have been particularly hard hit by HIV, experiencing a 34-percent increase in estimated incidence of HIV cases in their age group from 2006 to 2009. This spike reflects, in part, the sense of invincibility common to this age group, but also the realities many YMSM face, which commonly include histories of sexual abuse and engagement in sexual activity at an earlier age and with higher levels of risk. They also are more likely to live in poverty, have limited educational attainment, and engage in survival sex and/or sex work.

Perhaps most alarming is that MSM generally do not consider themselves at risk for HIV, even though MSM of color have accounted for the majority of HIV/AIDS cases among MSM since 1998. The CDC’s Young Men’s Survey, conducted from 1994 to 2000, initially showed this disproportionate impact among YMSM of color. The survey found that Black, multiracial, and Hispanic YMSM were diagnosed with HIV at rates five, four, and two times that of their White counterparts, respectively. Of the YMSM of color who tested positive for HIV, 82 percent said they had no idea they were infected, and only 15 percent indicated being connected to HIV primary care and treatment. Most believed they were at little risk for HIV infection in their lifetime.
CONTINUING THE CONVERSATION:
ADDITIONAL ENGAGEMENT IN HIV CARE RESOURCES

The following lists additional resources related to the SPNS Program, marginalized and underserved PWLHA, and the theoretical foundations and practical application of the models of care discussed in this curriculum.

IHIP MATERIALS


Integration of Buprenorphine into HIV Primary Care Settings training manual, curriculum, and Webinars. www.careacttarget.org/iihip.

SPNS RESOURCES


Learn more about the following SPNS Initiatives that informed this curriculum at http://hab.hrsa.gov/abouthab/partfspns.html.

American Indian/Alaska Native (AI/AN) Initiative


Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color Initiative


Costs and Factors Associated with Turnover among Peer and Outreach Workers within the Young Men of Color Who Have Sex with Men SPNS Initiative. March 2010.


**Targeted Peer Support Model Development for Caribbeans Living with HIV/AIDS Demonstration Project**


Demonstration and Evaluation Models that Advance HIV Service Innovation Along the United States–Mexico Border

Special edition of the *Journal of HIV/AIDS and Social Services* featuring research about this initiative. October 8, 2008. Available at www.tandfonline.com/toc/jwhiv20/5/2.


**Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care**

Special edition of *AIDS Patient Care and STDs* featuring research about this initiative. June 2007. Available at online.liebertpub.com/toc/apc/21/s1.


**Prevention with HIV-Infected Persons Seen in Primary Care Settings Initiative**

Special edition of *AIDS Behavior* featuring research about this initiative. September 2007;11(Suppl 5). Available at www.springerlink.com/content/1090-7165/.


**Enhancing Linkages to Primary Care and Services in Jail Settings**


Enhancing Access for Women of Color Initiative


OTHER SPNS RESOURCES


OTHER HRSA, HAB RESOURCES
Download factsheets about the populations served by the Ryan White HIV/AIDS Program: http://hab.hrsa.gov/abouthab/populations.html.


OTHER ENGAGEMENT RESOURCES


Making the Connection: Promoting Engagement and Retention Into HIV Medical Care Among Hard to Reach Populations. Available at www.bu.edu/hd wg/pdf/projects/LessonLearnedFinal.pdf.


Naar-King S and Suarez M. *Motivational Interviewing with Adolescents and Young Adults*. 2011. Available at www.motivationalinterviewing.org.


OTHER JOURNAL ARTICLES


NOTES


31. CDC. Epidemiologic notes and reports immunodeficiency among female sexual partners of males with Acquired Immune Deficiency Syndrome (AIDS)—New York. MMWR. January 7, 1983;31(52):697–8


52. HRSA, HAB. Username: outreach worker. What’s going on @ SPNS. August 2006. Available at careacttarget.org/Library/SPNS Bulletin/spnsbulletin.aug06.pdf.


