



## ■ Defeating Stigma and Isolation: SPNS Homeless and Transgender Women of Color Initiatives

Throughout its history, the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau's (HAB's) Special Projects of National Significance (SPNS) Program has sought to focus its efforts on addressing barriers to care for populations disproportionately and most acutely affected by HIV. People in this group tend to have limited access to quality prevention and treatment services and to suffer from stigma and discrimination. Two populations at particular risk are (1) people who are homeless or unstably housed\* and multiply diagnosed with substance abuse or mental health issues and (2) transgender women of color.

These populations are the subjects of two new SPNS initiatives: the Building a Medical Home for Multiply Diagnosed HIV Positive Homeless Populations Initiative (Homeless Initiative) and the Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative (TWOC Initiative). Funding for both initiatives began in 2012 and will continue through 2017. Each initiative is supported by an Evaluation and Technical Assistance Center (ETAC) that will provide technical assistance to demonstration sites through various means, including regular teleconferences, initiative-specific Web sites and Webinar content, annual site visits, and semiannual national meetings to bring together all the grantees involved in each initiative.

### **SPNS Homeless Initiative**

#### *Background*

People living with HIV/AIDS (PLWHA) who are multiply diagnosed and unstably housed face not only homelessness and an HIV diagnosis but also a co-occurring mental illness or substance abuse problem. According to the U.S. Department of Housing and Urban Development's Annual Homeless Assessment Report (AHAR), in January 2010 the HIV/AIDS prevalence rate in the adult sheltered population was 3.9 percent, which is more than 5.5 times the rate in the general U.S. adult population and is nearing epidemic proportions.<sup>1,2</sup>

The 2010 AHAR also reported that 26.2 percent of sheltered adults had a severe mental illness, 34.7 percent had a substance abuse problem, and 12.3 percent were survivors of domestic violence.<sup>1</sup> In a study of homeless people in Los Angeles, California, two-thirds were chemically dependent and more than 1 in 5 was diagnosed with a mental health disorder, with significant overlap between the groups. Despite these significant health challenges, only 1 in 5 study participants had received any treatment for their health problems in the previous 2 months.<sup>3</sup>

The term homeless, which is often used as a catchall to describe any person experiencing difficulties securing permanent housing, is defined formally by the U.S. Government as anyone who lacks a fixed, regular, and adequate nighttime residence. The issue of housing stability is nuanced, however, and its influence on HIV risk cannot be fully appreciated without incorporating the broader population of those who are unstably housed, defined as those who (1) have not leased, owned, or occupied permanent housing within the past 2 months; (2) have experienced persistent housing instability (i.e., two moves or more during the preceding 2 months); and (3) are not expected to change their housing status at any point in the near future.<sup>4</sup> People fleeing domestic violence can also be considered unstably housed if they do not have the resources and support to obtain other permanent housing.<sup>4</sup>

\*For the purposes of this issue of *What's Going on @ SPNS*, "homeless" refers to both homeless and unstably housed people unless these groups are otherwise differentiated.

## *Demonstration Projects*

In 2012, SPNS Homeless Initiative grants were awarded to nine demonstration projects to design, implement, and evaluate innovative interventions to improve timely entry, engagement, and retention in HIV care and supportive services for HIV-positive homeless populations. In addition to evaluating their own demonstration projects, grantees will participate in a multisite evaluation study coordinated by the Boston University School of Public Health ETAC.

The homeless and unstably housed population has long been a subject of HIV prevention and treatment efforts. Thus it comes as no surprise that, although the SPNS Homeless Initiative is still in its infancy, the grantees supporting it are seasoned Ryan White providers who are well versed in the issues and challenges surrounding this high-risk population. To facilitate access by homeless and unstably housed PLWHA to a continuum of care tailored to their distinct needs, Homeless Initiative grantees will seek to implement models of care that build and maintain sustainable linkages to mental health and substance abuse treatment, access to housing resources and services, and HIV/AIDS primary care.

## **SPNS TWOC Initiative**

### *Background*

The term transgender refers to people whose gender identities differ from their biological gender at birth. Transgender people come from every walk of life, every sexual orientation, and every region of the country. Some may identify not as transgender but simply as male or female, or they may choose not to identify with any gender labels at all. Transgender people may seek to alter their bodies in a variety of ways or they may decide against any medical intervention.

A transgender woman (also known as male-to-female, or MTF) is a woman assigned male at birth but who identifies as a woman and expresses a female gender identity. Identifying transgender people for the purposes of collecting uniform HIV surveillance data is complicated by the intricacies and sensitivities of gender identity. For example, some people in the TWOC community may not self-identify as transgender. In part because of these challenges, the U.S. Centers for Disease Control and Prevention (CDC) does not yet report HIV surveillance data for transgender people, who have been classified instead as men who have sex with men. To improve reporting accuracy, the CDC recommends using a two-step method of asking for both sex assigned at birth and current gender identity when collecting surveillance data.<sup>5</sup>

Local and regional HIV surveillance data underscores that TWOC are a population grossly underserved and at very high risk for HIV infection.

- Data from CDC-funded HIV testing programs show high rates of new HIV infections among transgender people in the United States, whereas in the general U.S. population new HIV infections have remained relatively stable for several years. In 2009, the rate of newly identified HIV infection was 2.6 percent among the transgender population, compared with 0.9 percent for men and 0.3 percent for women in the general U.S. population.<sup>5</sup>
- The highest percentage of newly identified HIV infection in transgender people was among people of color, with African-Americans at 4.4 percent and Hispanics at 2.5 percent.<sup>5</sup>
- HIV prevalence is particularly high among younger TWOC between the ages of 15 and 25, with estimated rates ranging from 19 percent to 22 percent.<sup>7,8</sup>

### *Demonstration Projects*

Spurred by these alarming statistics, the TWOC Initiative was created to develop and test innovative interventions to improve timely entry, engagement, and retention in quality HIV care for TWOC who are living with or at risk for HIV. Grants were awarded to nine demonstration projects. The grantees will work with an ETAC led by the University of California at San Francisco. The TWOC Initiative hopes to engage both HIV-negative TWOC at high risk of HIV infection and those who may already be infected with HIV but are unaware of their HIV status, have never been engaged in care, have refused referral to care, or have dropped out of care.

A CDC-funded meta-analysis estimated that HIV prevalence among transgender women was nearly 12 percent for those who self-reported their status (across 18 studies), but that estimated prevalence for those who were HIV tested was much greater, at nearly 28 percent (across 4 studies).<sup>6</sup> This research also suggested that between 45 percent and 65 percent of HIV-positive transgender women may be unaware of their HIV status. And where awareness is low, risk is high. A study by the CDC and Johns Hopkins University found that PLWHA who were unaware of their HIV status had a transmission rate 3.5 times higher than that of those who were aware of their status; PLWHA who were unaware of their HIV status accounted for more than half of all new sexually transmitted HIV infections.

## **Shared Solutions to Distinct Challenges**

For both the Homeless and the TWOC initiatives, grantees will collect and report quantitative and qualitative outcome, process, and cost metrics for their interventions. This information will include client demographic characteristics; biomedical and behavioral health indicators; barriers to accessing treatment and services; and utilization of core medical and support services, such as those

for substance abuse, mental health, and housing assistance. To ensure project sustainability, grantees will develop strategies for maintaining access to HIV care and treatment for the target populations beyond the SPNS grant period.

The basics of delivering quality HIV care remain relevant to the care and treatment of the homeless and TWOC populations, as they do to all populations at high risk of HIV infection. A one-size-fits-all mentality, however, does not work with these populations, due to the complexity of issues affecting individuals in these populations. To be effective, efforts to engage them in care must be culturally competent and tailored to their unique needs.

The SPNS program is always seeking strategies by which SPNS grantees can adapt the fundamentals of wraparound, culturally competent HIV services to address the distinct challenges of their target populations. The unique application of some of these fundamentals of care within the Homeless and TWOC Initiatives is described below.

### *Intensive Care Coordination*

As part of the TWOC Initiative, demonstration projects are required to create or enhance an existing referral network to link TWOC with the services they need to remain in care. Much like their counterparts in the Homeless Initiative, many patients enrolled in the TWOC Initiative are in need of care and support for more than their HIV diagnosis alone. In one New York study of people newly diagnosed with HIV, half of all transgender women had documentation in their medical records of substance use, sexual abuse, commercial sex work, homelessness, or incarceration, compared with 31 percent of people who were not transgender.<sup>5</sup> TWOC Initiative grantees will seek to link TWOC with appropriate services, such as mental health and substance abuse treatment, to address these and other related barriers to proper HIV care.

The Butterfly Project of the Institute of Public Health in Oakland, California, a TWOC Initiative grantee, provides an example of intensive care coordination in action. One way in which the Butterfly Project plans to support TWOC in Oakland and surrounding Alameda County is by operating a safe place for TWOC called the Butterfly Nest. “The Butterfly Nest will offer motivational enhancement counseling, health promotion workshops, and weekly support groups for TWOC as well as referral services for HIV testing and HIV primary care to the collaborating agencies,” says Butterfly Project director Tooru Nemoto. “It’s this kind of comprehensive treatment that our transgender clients need because they are coming to us with a number of challenges like incarceration, housing issues, mental health, substance abuse, and sex work,” he adds.

One Homeless Initiative grantee, the Medical Home Engagement and Aligning Lifestyles and Transition from Homelessness (mHEALTH) Program at the Yale University AIDS Program, knows

from experience how important comprehensive, wraparound services are to its patients. The mHEALTH Program is built in part upon lessons from another SPNS initiative, Enhancing Linkages to HIV Primary Care and Services in Jail Settings (Jails Initiative), which was funded from 2007 to 2012. (To learn more about the Jails Initiative, see <http://hab.hrsa.gov/about/hab/special/care-jail.html>). Results from that initiative and other studies plainly demonstrated that housing instability remains a huge issue for PLWHA who cycle in and out of the criminal justice system, which remains the most common point of origin for people entering U.S. homeless shelters.

### *Increasing Access to Stable/Permanent Housing and Employment*

Although homelessness may not be the primary focus of the TWOC Initiative as it is for the Homeless Initiative, housing instability is a major barrier to care for many HIV-positive transgender women. Transgender people are 4 times more likely than the general population to have a household income of less than \$10,000 per year, and unemployment among transgender people of color is more than 4 times the national average.<sup>11</sup> In addition, 1 in 5 transgender people has been homeless in the past.<sup>11</sup> According to a study of 151 young minority transgender women in Chicago and Los Angeles, as many as 67 percent of TWOC have been involved with the sex and drug trades at some time in their lives.<sup>12</sup>

Chicago House is a Chicago-based nonprofit that offers programs to address the needs of people who are disproportionately affected by HIV/AIDS and economic and health disparities, including minorities and the lesbian, gay, bisexual, and transgender community. Recently, Chicago House launched the TransLife Project, a demonstration project for the TWOC initiative. Chief among the TransLife Project’s offerings will be the TransLife Center, which will be established in the renovated former Chicago House hospice. “The TransLife Center is in a sacred space, as literally over a thousand mostly gay men lost their lives within these walls in the early years of the AIDS epidemic,” says Chicago House’s chief executive officer, Reverend Stan Sloan.

The TransLife Center will be complemented by five programs for the transgender population:

- 1. TransHousing:** Residential housing will include 9 bedrooms within the center itself as well as 36 scattered-site housing units supported by the Chicago House housing program. “TransHousing is modeled after another program we had on the West Side of Chicago, which had a return to homelessness of 0 percent over the past 5 years,” says Sloan.
- 2. TransWorks:** A 4-week job-training program for transgender people builds on the foundation of the groundbreaking Chicago House employment program for PLWHA. After graduation from the training program, participants will be assigned

to a career counselor who, like all staff members working at the TransLife Center, will be from the transgender/gender-nonconforming community. The career counselor will help guide members through trainings related to transgender issues in the workplace, such as changing ID cards to reflect a member's preferred gender and navigating issues related to gender-specific workplace bathrooms. Legal rights in the workplace will also be discussed.

**3. TransHealth:** The TransLife Center will house a doctor's office that will be staffed part-time by Rob Garofalo, an attending physician at the Ann and Robert H. Lurie Children's Hospital of Chicago, and his coworkers. Garofalo is also director of the hospital's Adolescent/Young Adult HIV Program and its Center for Gender, Sexuality, and HIV Prevention. The office will provide routine HIV testing and linkages to other medical care.

**4. TransLegal:** Owen Daniel-McCarter, founder of the Transformative Justice Law Project of Illinois, will be joining staff of the TransLife Center to open its TransLegal Services Clinic. Daniel-McCarter will coordinate with local law firms and organizations to help the community with name changes, clearing criminal records, workplace suits, and other legal issues facing the local transgender community.

**5. TransSafe:** The TransLife Center will provide a safe haven for individuals who simply need a respite from life on the streets and any discrimination or harassment they may be encountering.

### *Culturally Competent Care*

Historically, the relationship between the transgender and health care communities has been strained by misunderstanding. For this reason, the TransHealth Program will ensure that it connects patients with transgender-friendly medical providers who have been trained by the program to be culturally competent in transgender issues. This step helps reduce a huge burden to care for TransLife's transgender clients, many of whom have experienced some abuse or discrimination at the hands of the medical community in the past. In a recent study by the National Center for Transgender Equality, nearly 1 in 5 transgender people reported being refused medical care because of their transgender or gender-nonconforming status, and more than half said they had to educate their own providers about transgender care.<sup>11</sup> Past experiences with provider insensitivity and hostility have caused some transgender women to avoid the health care system entirely.<sup>8,13,14,15</sup>

At the mHEALTH program, patients are linked with both a network navigator and a peer navigator. "The network navigator is someone who really understands the complex array of services provided, more on a professional level," says Frederick Altice, mHEALTH project director. The peer navigator, on the other hand, is a peer in

the community. "They are not necessarily someone who is homeless but it might be someone with HIV, and it definitely will be someone who is culturally competent and understands the real-life issues our homeless patients face," adds Altice.

Perhaps the most visible barriers to culturally competent care arise in the treatment of PLWHA from other countries, who may face the added burdens of not understanding English, American customs, or U.S. health systems. CommWell Health Medical Home Works (CWMH) in rural southeast North Carolina, a SPNS Homeless Initiative grantee, serves a large migrant farm-worker population, 60 percent of which are homeless or unstably housed. In addition, "90 percent of the farm workers we serve are male, monolingual (speaking only Spanish), low-acculturated Latinos with low [levels of] education," says Jesus Felizzola, CWMH principal investigator. Thirty-two percent of CWMH staff is bicultural and bilingual, speaking both Spanish and English fluently. "Those dealing on a face-to-face basis with patients are all bilingual," says Felizzola. "They know the target population very well. They have an enormous capability to treat this population in their native Spanish and address issues of linguistic and cultural competency."

### **Good Things to Come**

Although the SPNS Homeless and TWOC Initiatives will end in 2017, the broader impact of their work on other Ryan White providers will be just beginning. The challenges faced by these high-risk populations persist, making all the more vital the need for innovative and evidence-based approaches to dismantling barriers to HIV care. The work of these grantees will identify best practices in HIV care that can be replicated by both other Ryan White providers and the health care community at large.

### **SPNS Homeless Initiative Grantees**

- AIDS Arms, Inc.; Dallas, TX
- Pasadena Public Health Department; Pasadena, CA
- Family Health Centers of San Diego; San Diego, CA
- San Francisco Department of Health Services; San Francisco, CA
- CommWell Health Medical Home Works; Newton Grove, NC
- University of Florida Center for HIV/AIDS Research, Education and Service; Jacksonville, FL
- Yale University AIDS Program; New Haven, CT
- Harris County Hospital District; Houston, TX
- Multnomah County Health Department; Portland, OR
- Boston University School of Public Health; Boston, MA (Evaluation and Technical Assistance Center)



## SPNS Transgender Women of Color Initiative Grantees

- BIENESTAR Human Services, Inc.; Los Angeles, CA
- San Francisco Department of Human Services; San Francisco, CA
- Public Health Institute; Oakland, CA
- Tri-City Health Center; Fremont, CA
- Howard Brown Health Center; Chicago, IL
- Chicago House and Social Service Agency; Chicago, IL
- Community Healthcare Network; New York, NY
- The Research Foundation of SUNY/SUNY Downstate Medical Center; Brooklyn, NY
- Friends Research Institute, Inc.; Baltimore, MD
- University of California, San Francisco; San Francisco, CA (Evaluation and Technical Assistance Center)

### For More Information

For additional information on the SPNS Homeless and Transgender Women of Color Initiatives, visit <http://hab.hrsa.gov/about/hab/partfspns.html>. The SPNS Project Officers for these initiatives are:

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## Ryan White Voices

A Transgender Women of Color Initiative grantee will be featured in an upcoming video on the Ryan White Voices section of the HRSA HIV/AIDS Bureau's A Living History: A Legacy of Care Web site. To learn more, please visit: [www.hab.hrsa.gov/livinghistory/voices/index.htm](http://www.hab.hrsa.gov/livinghistory/voices/index.htm).