



What's Going on @ SPNS



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How SPNS Initiatives Support the Fight against HIV Stigma

“Stigma helps make [HIV] the silent killer.”¹

—United Nations Secretary-General Ban Ki-moon

After more than 30 years of fighting HIV, a veil of silence and shame still surrounds the virus. People living with HIV (PLWH) are still being forced to use plastic utensils, ostracized by neighbors and colleagues, kicked out of residences, denied or fired from jobs, and accused of promiscuity or other deviant behavior. A team member at a Chicago, IL, Ryan White HIV/AIDS Program site says many patients even feel the impact of stigma within their own families: “We have [patients] . . . their mothers won’t hug them without gloves on,” says Allison Precht of The Ruth M. Rothstein CORE Center.²

As a result, some PLWH — especially those who live in small, tight-knit communities — will travel long distances to see HIV specialists because they don’t want people to see them engaging in care. They slip into clinics using back doors or wait until after hours so they won’t run into someone they know in waiting rooms.

Others keep the diagnosis a secret for years, terrified to tell anyone other than their care providers. They may hide their medications from roommates and even family members. One woman living with HIV who receives care at a Ryan White HIV/AIDS Program clinic in Denver, CO, has never told her twin sister that she is HIV positive.

Even health care workers have been shown to stigmatize patients with HIV. A survey of health care professionals in Los Angeles County found that 56% of skilled nursing facilities, 47% of obstetricians, and 26% of plastic and cosmetic surgeons have refused to treat people living with HIV.³

PLWH tend to internalize stigma, leading to intense feelings of shame and fear. In fact, research shows that HIV-associated stigma is often the main reason why people are reluctant to be tested or disclose their HIV status.⁴ PLWH who encounter high levels of stigma also are more likely to report inadequate access to care and medication adherence.⁵ The result is a vicious cycle of increased infectiousness and poor health outcomes because people who do not know their status are more likely to transmit the virus, and those who do know, but are fearful about disclosure, are more likely to avoid treatment.^{6,7}

Stigma at 30 Years

According to a 2011 survey, the percentage of Americans who would not want to . . .

- Eat food prepared by someone who is HIV-positive **45%**
- Live with an HIV-positive roommate **36%**
- Have their child taught by an HIV-positive teacher **29%**
- Work with someone who is HIV positive **18%**

Source: The Henry J. Kaiser Family Foundation (KFF). HIV/AIDS at 30: a public opinion perspective. June 1, 2011. Available at: <http://kff.org/hiv/aids/report/hiv-aids-at-30-a-public-opinion-perspective/>.

Many Layers of Stigma

Stigma is both destructive and multilayered. Several subpopulations that have the highest risk of HIV infection often face multiple sources of stigma, and that can make it even harder for them to access and stay in care. For example, stigma around behaviors such as drug use or sexual activity can cause patients to not be forthcoming with clinicians.⁸ People of color, men who have sex with men (MSM), transgender and other gender-nonconforming individuals, and individuals who struggle with

mental health disorders or unstable housing all face additional discrimination. This kind of double or even triple stigmatization for marginalized groups compounds the feelings of ostracism and isolation that can compromise care.⁹

Stigma is such a significant obstacle to care that the National HIV/AIDS Strategy (NHAS) cites efforts to combat it as a critical step in reducing HIV-related disparities and health inequities.¹⁰ Meeting that NHAS directive requires doing more for the groups and communities that bear the greatest burden of disease. This has been a focus of the Ryan White HIV/AIDS Program, administered by the Health Resources and Services Administration's (HRSA's) HIV/AIDS Bureau (HAB), since its inception. The idea is to provide comprehensive support for PLWH; helping them overcome interpersonal stigma and working to reduce systemic stigma is a major part of that effort.

HAB's Special Projects of National Significance (SPNS) Program plays a special role in combatting stigma. Over the years, many SPNS initiatives have involved targeted interventions to develop evidence of best practice in engaging hard-to-reach populations and removing many barriers to care, especially one as persistent and challenging as stigma.

SPNS Helps Vulnerable Populations Cope with Stigma

Since its inception in the early 1990s, SPNS has been testing innovative models of care among populations disproportionately affected by HIV. Most recently, the SPNS Program has focused on funding models that help move vulnerable PLWH farther along the HIV Care Continuum. Some examples include:

- **Young MSM of Color.** The Outreach, Care, and Prevention to Engage HIV Seropositive Young Men Who Have Sex with Men (YMSM) of Color in HIV Care Initiative funded eight grantees from 2004 to 2009 to develop interventions designed to engage young MSM of color in care.
- **Women of Color.** The Enhancing Access to and Retention in Quality HIV Care for Women of Color (WOC) Initiative funded 10 grantees from 2009 to 2014 to help black/African-American and Hispanic/Latina women overcome barriers that keep them from accessing and staying in care.
- **Transgender Women of Color.** The Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color (TWOC) Initiative is funding nine grantees from 2012 to 2017 to develop interventions to improve timely entry into and engagement in care for TWOC.
- **Latinos.** The Culturally Appropriate Interventions of Outreach, Access, and Retention among Latino(a) Populations Initiative is funding 11 grantees from 2013 to 2018 to develop culturally

competent service delivery models that are specific to countries of origin.

- **Homeless and Unstably Housed Individuals.** The Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations Initiative is funding 10 organizations from 2012 to 2017 to develop and maintain sustainable linkages to both medical care and housing assistance.
- **Incarcerated Individuals.** The Enhancing Linkages to HIV Primary Care and Services Initiative funded 11 grantees from 2007 to 2011 to study innovative methods for linking PLWH who will soon be or have been recently released from jail settings into HIV care and services.
- **Injection Drug Users.** Two SPNS initiatives — for hepatitis C and buprenorphine opioid substance abuse treatment — funded interventions designed to engage and retain more HIV-positive IDUs into care.

Grantees involved in these and other SPNS initiatives have seen firsthand how stigma prevents many PLWH from engaging and remaining in HIV care: “There’s still this very negative image of HIV; that you did something to bring on this illness,” says Sandra Munier, program director for a WOC Initiative project at New North Citizens Council in Springfield, MA.¹¹ Another WOC grantee explains that stigma within their community is so high that during 20 years of working with HIV-positive people of color, she can count on one hand the number of them who have easily disclosed their status: “The fear of disclosing is almost overwhelming,” she says.¹²

This kind of fear is what drives people underground and contributes to delayed entry into care. It also contributes greatly to feelings of isolation and depression, according to Lisa Hightow-Weidman, M.D., an associate professor with the University of North Carolina's School of Medicine (UNC). Dr. Hightow-Weidman was involved in the UNC outreach project for YMSM of color called STYLE (Strength Through Youth Livin' Empowered). Although many YMSM of color who participated in the SPNS Initiative felt comfortable with their sexual orientation, they often felt uncomfortable identifying themselves publically as gay or bisexual because of fears of stigma, discrimination, and physical and emotional abuse. For that reason, participants reported often avoiding health care providers, on the belief that they might disclose their HIV status and sexuality without permission.^{13,14}

UNC's YMSM of Color Project has been sustained beyond the SPNS grant cycle through additional funding from the Centers for Disease Control and Prevention. As an ongoing program, STYLE continues to address stigma in multiple ways. First, it connects newly diagnosed young black MSM with clinic support groups to help them adjust emotionally to their diagnosis. If a young person is too nervous, however, to attend a group session (or can't for rea-

sons of time or transportation), a clinic social worker will connect him to a peer to provide personalized support. The program also provides patients with individual counseling. “A clinic social worker who works specifically with young MSM offers in person or over the phone counseling that deals specifically with issues of stigma, trauma, and acceptance,” says Dr. Hightow-Weidman. And just as important, the STYLE program ensures that clinic materials and providers create a welcoming environment by using and offering culturally competent messaging and care.

The Importance of Cultural Competency

Stigma arises in part from a lack of understanding of a population and its needs.¹⁵ Thus, providing culturally competent care is a cornerstone of SPNS grantees’ efforts to combat stigma, and they make sure staff members are trained to recognize the socio-cultural factors that can prevent PLWH from fully engaging in care.

Engaging Latino Populations

Interventions for the Latino Initiative, for example, addressed several of the socio-cultural and structural barriers, especially stigma, that affect Latinos’ access to and retention in HIV primary care. “There are several specific Latino cultural constructs that can factor into how many Latinos seek and obtain health care,” says Jessica Xavier, a SPNS project officer.¹⁶ Consider these examples.^{17,18}

- *Machismo* is a Spanish term for the Latino construct of idealized masculinity and traditional gender roles. Latino men at risk for HIV or exposed to HIV through other risk factors, such as heterosexual sex or injection drug use, may fear disclosing their behaviors or HIV-positive status for fear of being identified—or misidentified—as homosexual.
- *Marianismo* is a female gender construct that idealizes feminine passivity and submissiveness to men as well as sexual purity. This may prevent Latinas from accessing HIV testing and care and negotiating for safe sex practices with their male partners.
- *Fatalismo*, the Spanish term for fatalism, is the idea that God ordains all life events, and thus HIV infection is often considered a judgment only God can heal. This belief may inhibit some Latinos with strong religious beliefs from seeking out or adhering to medical care.

Non-English Speakers

Perhaps the most visible barriers to culturally competent care involve treating PLWH from other countries, who may struggle to understand English or American customs. Even providing translators sometimes isn’t enough. “One of the things that we hear from our patients is, ‘I don’t like when the translator is there because she doesn’t say exactly what I’m telling her,’ says Munier of New North Citizens Council in Massachusetts.¹⁹ “There is still a ‘disconnect’ because we make an assumption that [the translator] is meeting the need, but a lot of times the person who

you’re translating for is sitting there frustrated.” This is a situation where grantees have found it helpful to have bilingual care providers or to rely on a peer advocate, someone who patients are more likely to trust.

Transgender

Transpeople also face an enormous amount of stigma, which can lead to lower self-esteem, depression, and increased likelihood of survival sex work, substance abuse, and risk-taking behaviors.²⁰ In addition, many have had negative past experiences with the health care system due to the insensitivity, ignorance, or discomfort of medical providers, creating further barriers to engagement and retention in care.²¹ For this reason, the Chicago House and Social Service Agency, a SPNS Transgender Women of Color Initiative Grantee, is ensuring 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 barrier to care for the agency’s transgender clients, as one study found that nearly 27% of transpeople reported experiences of discrimination in health care because of their transgender or gender non-conforming status.²²

African-Americans

Within some parts of the African-American community (particularly in the South), deep levels of distrust for the medical community exist. This profound level of distrust, related in part to the lingering impact of the Tuskegee experiments and other discriminatory practices,²³ often leads to a lack of engagement in care.^{24,25} Black immigrant populations also face additional language and cultural barriers to care. Some may fear arrest due to immigration issues, while others are reticent to seek care due to the ongoing association of HIV with the Caribbean and Africa.²⁶

Empathy is Key

Above all, grantees have found that empathy is critical in the fight against stigma. “STYLE ensures that all providers embrace the concept of ‘cultural empathy,’” says Dr. Hightow-Weidman. “While we may not have walked in the shoes of our patients or experienced what they have in their lives (including any of the stigma they experience), we must strive to have compassion and understanding and to ensure that we address how these stigma impact care.”

Learning from Successful Interventions

Over the years, SPNS grantees have tested a myriad of interventions designed to overcome the impact of stigma. Linking PLWH to mental health services (either internally or through referrals) to help them cope with the impact of stigma has been, in some instances, a first step. It is important, however, to recognize that accessing mental health services can carry stigma within some

communities. Providers will need to address this barrier up front to increase the use of these services.

Other tactics, as reported by grantees across multiple SPNS initiatives, include:

- Developing safe spaces that avoid “HIV” branding and create a greater sense of anonymity.
- Providing public, as well as patient, education around HIV is essential for countering longstanding and entrenched stigma and misinformation.
- Communicating to patients that the law requires all providers to maintain patient confidentiality.
- Assisting patients in navigating complex health care systems to ensure that stigma does not interfere with accessing services.
- Relying on peers to serve as role models for overcoming stigma and fully engaging in care.
- Identifying training opportunities to develop cultural competency (including front desk staff members who are often the first person patients interact with at the clinic).
- Hiring individuals who come from the same communities as potential patients do.
- Recognizing that while particular subpopulations may have shared experiences, each person is unique, so it is important to listen carefully and assess individual needs.
- Forming a consumer advisory board to collect patients’ input.
- Arranging gender-neutral bathrooms (this is particularly important if a clinic is treating transgender patients).
- Making sure that forms ask for preferred names and gender identification.
- Normalizing the offer of screenings (e.g. for substance abuse, mental health, intimate partner violence, etc.) so patients don’t feel judged or targeted.

Many grantees have also relied on support groups to help PLWH cope with stigma. Stories from support groups highlight the fellowship and hope these forums can provide, thus strengthening engagement and retention in care. For instance, Allison Precht of the CORE Center says it was common to hear during staff debriefings that a woman shared something in her support group that she’d never shared with anyone before. “The thing is,” she says, “they lifted each other up.”²⁷

Building Capacity to Fight Stigma

Through its various initiatives, the SPNS Program has helped grantees develop and implement interventions that build capacity for fighting stigma both within their organizations and among their

Motivational Interviewing

SPNS grantees have used Motivational Interviewing (MI), a form of culturally competent counseling, to encourage people living with HIV (PLWH) to examine their own motivations for knowing their HIV status, thereby helping them feel more involved in their testing, treatment, and care experiences.

The core of MI is helping PLWH identify behavior changes they want to make and the issues that get in the way of making those changes.²⁸ Thus, MI can be a helpful technique for helping PLWH cope with external stigma and overcome internalized stigma.

For more information about MI, see the June 2010 issue of *What’s Going On @ SPNS* about Creating Change: Using Motivational Interviewing in SPNS Projects, at http://hab.hrsa.gov/about/hab/files/cyberspns_motivation.pdf.

communities at large. Evidence-based documentation ensures that other providers can replicate these successful models as well.

The ultimate goal is to end persistent stigma, so that PLWH can get the care they need to reduce transmissions and live healthier lives.

For More Information

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