



What's Going on @ SPNS



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❖ Breaking Barriers, Getting YMSM of Color Into Care: Accomplishments of the SPNS Initiative

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 School of Medicine

The words above speak to the very heart of the Ryan White HIV/AIDS Program, which provides a lifeline to people living with HIV/AIDS (PLWHA). To improve service delivery and ensure increased access to care and treatment for PLWHA, the Ryan White HIV/AIDS Program's Special Projects of National Significance (SPNS) Program supports innovative models of care and the development of effective HIV service delivery systems that otherwise would not be funded, evaluated, or replicated.^{1,2} The SPNS initiative Outreach, Care, and Prevention to Engage HIV Seropositive Young Men Who Have Sex with Men (YMSM) of Color in HIV Care, which took place from 2004 through 2010, exemplified this mission.

Eight demonstration projects in geographically diverse regions—from Rochester, New York, to Los Angeles, California—were selected to create and implement interventions to engage YMSM of color in care. The goals of the intervention included (1) conducting outreach to help seropositive YMSM learn their HIV status; (2) linking HIV-infected YMSM with medical care and supportive services and (3) preventing transmission of HIV infection.³

The George Washington University (GWU) School of Public Health and Health Services' Youth Evaluation Services (YES) Center served as the initiative's evaluation and technical assistance hub. The GWU YES Center coordinated a multisite evaluation of the models' effectiveness in reaching and engaging HIV positive YMSM of color in clinical, supportive, and preventive services.⁴

YMSM of Color and HIV

The need for this initiative stems from the urgency around the impact of HIV on YMSM of color. Although MSM represent only 4 percent of the male population in this country age 13 and older, the U.S. Centers for Disease Control and Prevention (CDC) reported that they accounted for 61 percent of new HIV infections in 2009. As a group, YMSM ages 13 to 29 have been particularly hard hit, experiencing a 34 percent increase in new HIV cases from 2006 to 2009.⁵

MSM of color of all ages 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, first showed the disproportionate impact of the disease on YMSM of color. The survey found that Black, multiracial, and Hispanic YMSM are 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.⁶⁻⁸ Most had believed they were at little risk for HIV infection in their lifetime.

Lack of access to HIV/AIDS awareness and education, coupled with the effectiveness of highly active antiretroviral therapy (HAART), has helped foster complacency about AIDS among YMSM of color, encouraging high-risk behavior and fueling infection. Statistics released by the CDC in July 2011 indicate that in 2009, YMSM ages 13 to 29 represented 60 percent of new HIV cases among Black MSM and 45 percent of cases among Latino MSM.⁵ These numbers are of particular concern because YMSM of color tend to get tested and to be diagnosed with HIV later in the course of the disease than their White counterparts, making them more likely to transmit the virus unknowingly to others and ultimately progress to

AIDS. They also enter HIV primary care later, if at all, undermining the efficacy of their treatment and health outcomes.^{9,10}

YMSM Initiative Grantees: Unique Approaches to Intervention

The eight YMSM of color initiative grantees included two universities, four community-based AIDS service organizations, and two county health departments. The biggest challenge each grantee faced in testing its model of HIV care and service delivery was the barriers that prevent many YMSM of color from accessing HIV primary care and treatment in the first place. YMSM of color face individually the same socioeconomic issues that affect their communities as a whole, including poverty, racism, limited or no health insurance, lack of transportation, homelessness, substance use, under- or unemployment, limited education attainment, and low health literacy.^{11,12}

Although many YMSM of color who participated in the initiative felt comfortable with their sexual orientation, they often felt uncomfortable identifying themselves publicly 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} As Thomas Giordano, a physician with the Harris County (Texas) Public Health and Environmental Services demonstration site, explains,

YMSM of color are vulnerable to HIV for many reasons. They have trouble linking and staying in care, in part just by virtue of being young, leaving them more susceptible to stigma, psychiatric disease, and substance use. [They also] have limited experience accessing services in a fragmented health care system.

Overcoming barriers to care was essential to the success of the YMSM of color interventions.

YMSM Interventions in Action

Each grantee engaged in innovative recruitment and intervention strategies to identify and engage YMSM of color in HIV testing, care, and treatment services. Strategies included social outreach, motivational interviewing, Internet-based interventions, and “in-reach” at local health care and youth-focused service systems to identify HIV-positive YMSM of color who had fallen out of care.

Social Outreach

Social outreach efforts included sending outreach workers on foot or in testing vans to venues believed to be popular with YMSM of color. The demonstration sites reported that they reached many YMSM of color in this way and undoubtedly helped raise awareness about HIV/AIDS and normalize the idea of getting tested among all members of the local community. Sites offering rapid testing had more success getting YMSM of color to participate; one

SPNS YMSM Demonstration Sites

- AIDS Project East Bay, Oakland, CA: www.apeb.org/
- Bronx AIDS Services, Bronx, NY: www.basnyc.org
- Harris County Public Health and Environmental Services, Houston, TX: www.harriscountyhealth.com/
- Los Angeles County Department of Public Health, Office of AIDS Programs and Policy: www.publichealth.lacounty.gov/aids/
- Men of Color Health Awareness Project, Buffalo, NY: <http://mochacenter.org/>
- University of North Carolina, Chapel Hill: www.unc.edu/index.htm
- Wayne State University, Detroit, MI: www.wayne.edu/
- Working for Togetherness, Chicago, IL: www.workingfortogetherness.org/
- George Washington University (Evaluation Center): www.yes-center.org/

site reported that recruited youth returned to the testing location with their peers.

One drawback of social outreach was that identifying YMSM of color in recreational settings proved challenging. Outreach workers required intensive training and worked long hours, often without yielding as many participants as expected. Much of the testing identified HIV-negative YMSM of color whose behaviors put them at high risk for infection later, prompting one group to conduct follow-up testing.

Some sites also reported not finding YMSM of color in the areas designated or finding only MSM who appeared younger than their age. Most YMSM of color engaged by the sites were receptive to their messages but felt uncomfortable discussing HIV in public, preferring to be tested in a health clinic or, even better, a private doctor's office.

Motivational Interviewing

Grantees successfully enlisted participants through a combination of traditional outreach and motivational interviewing (MI). This process involved not only providing information about HIV testing but also offering individualized counseling and encouragement to get tested and engage in care. The outreach was conducted by specially trained personnel, most often a peer or near-peer—another YMSM of color who was the same (or close in) age and had a similar cultural or linguistic background.¹⁵ During these encounters, the outreach workers encouraged participants to examine their intrinsic motivation to know their HIV status,¹⁶ thereby helping them feel more involved in their testing, treatment, and care experiences.

A challenge with motivational interviewing is that although it is effective for recruitment, it requires extensive training in which outreach workers and peers practice their skills in a controlled environment and a third-party to review tapes of their interactions with participants. High rates of staff turnover at sites, especially among peers, required training new people on two occasions.

Internet-Based Interventions (Chat Rooms and Social Networking Sites)

Online chat rooms and social networks were rapidly developing when the YMSM of color initiative began in 2004. Incredibly popular with young people, including YMSM of color, the semiprivate and potentially anonymous world of online communities appeared to be an untapped vehicle to recruit YMSM of color into HIV testing, treatment, and primary care. One site conducted a successful online survey of its YMSM audience with the assistance of the GWU YES Center, and others used peers to disseminate health messages and invite people to ask health questions in chat rooms used by MSM to recruit sexual partners.

Unfortunately, many of the demonstration sites found the technology of the Internet social networking venues available during the grant period unwieldy for recruitment purposes. As with the face-to-face encounters in public places, most of the online users appeared reluctant to interact with outreach workers in public online arenas because of concerns about their privacy. Sites also found that YMSM of color, who tended to move around and have limited funds, often had only intermittent Internet and mobile phone access. Maintaining constant contact with them by texting, e-mail, and other electronic mechanisms proved almost impossible.

In-Reach

Some grantees conducted in-reach through local health care and youth-focused service systems to identify HIV-positive YMSM of color who had fallen out of care. Nearly all the sites reported that this approach was most efficient and successful for identifying participants for their intervention. Some grantees coupled this approach with HIV testing efforts in emergency rooms, sexually transmitted disease clinics, health clinics, and other health care settings where YMSM often go for non-HIV related services.

The only drawback to in-reach was that it did not identify new YMSM of color in the community. In addition, to ensure that they were not lost once again, providers needed to address the issues facing the YMSM of color who are brought back in to care.

All the demonstration sites engaged in intensive planning before moving forward with their interventions. Several grantees engaged members of their local target population in focus groups, a process that provided insight into perceived barriers to care and what YMSM thought would best promote HIV care in their communities and improve service delivery.

Together, the demonstration sites identified almost 400 HIV-positive YMSM and engaged them in nearly 1,000 follow-up interviews. Nearly 70 percent of the YMSM of color engaged were Black, 21 percent were Hispanic, and the remainder were of mixed race/ethnicity. All were confirmed HIV positive, between ages 13 and 24, born male, and not in care 3 months prior to recruitment. The bulk of participants were 18 and older; all sites experienced difficulties recruiting YMSM of color who were ages 13 to 17.¹¹

Connecting YMSM to Care

Almost all the demonstration sites engaged YMSM of color who tested positive for HIV directly into care. These immediate linkages were essential, because many youth had unstable living situations, little familial support, and limited experience with the health care system. One demonstration site carefully coordinated local HIV surveillance personnel and care providers, who traditionally had not worked together. In this scenario, YMSM of color who tested positive were informed of their diagnosis and then immediately “handed off” to a waiting case manager, who initiated necessary primary care and treatment linkages. Another site focused on intensive engagement with its participants, placing them with a youth-focused case manager who took detailed assessments of their lives, identified potential barriers to care, and created an individualized treatment plan that addressed those barriers. This plan was followed up with intensive, individualized meetings that occurred several times a month for 2 years.

Many sites bolstered these intense engagement approaches by providing transportation to initial appointments, maintaining contact through followup, openly addressing treatment adherence issues, and providing medication education. Grantees often provided participants with additional referrals, as needed, to nutritional support, housing, mental health, and substance abuse treatment services. This “hands-on” approach, according to Amy Wohl, Chief Epidemiologist at Los Angeles County Department of Public Health, proved essential to retaining YMSM of color in care. She and her colleagues were surprised at the start of the initiative to find a population in what she described as a “state of crisis”:

When they came in, so many had such serious problems. Fortunately, they developed a rapport with their case manager, who was peerlike and sensitive to their needs. She understood the situations of youth—and the stigmatization of HIV and MSM behavior—in Latino and African-American communities and helped them navigate those issues. Indeed, it was critical to the success of the program.”

Some challenges were common across the demonstration sites, most notably involving peer educators, many of whom were full-time employees who required specialized training. As the project period progressed, many peers outgrew their roles and moved on to new positions. Others, as young people new to the workplace, did not have a mature work ethic and had to be let go. Replacing

peers required grantees to expend significant training resources, which proved expensive in terms of staff hours. One organization reported that its youth did not readily respond to peers but connected unexpectedly with an older female caseworker, who gained their trust by showing genuine care about their needs.

Moving From Demonstration Project to Permanent Program

Each demonstration site conducted its own local evaluation to assess its recruitment and retention-in-care activities. Many sites were able to keep 70 percent or more of the HIV-positive YMSM of color they identified in care for a year or more. They also alerted the GWU YES Center and the Health Resources and Services Administration HIV/AIDS Bureau of approaches that did not work as planned, such as peer referrals (which never gained momentum at most of the demonstration sites) and online outreach (which failed to yield as many participants as other methods). The evaluation provided essential information about the real-world applications of each proposed model of care.

On a national level, the GWU YES Center team had the unique challenge of evaluating demonstration projects in different geographic locations, each with unique target population(s) and diverse organizational structures. One way in which the GWU YES Center overcame this challenge was to create a centralized Web portal, where grantees and other interested parties could share information and download resources. The GWU YES Center also facilitated grantee meetings, where staff provided technical assistance and encouraged the participants to share lessons learned and support through a model called peer-to-peer technical assistance.

Julia Hildago, who headed the GWU YES Center, says much of the grantees' success stemmed from their cooperation. She explains,

They really worked together—there was never “an us-versus-them” mentality. GWU helped facilitate network building, and by the second grantee meeting, the demonstration sites were emailing and visiting each other in person. We also organized visits to local sites engaged in similar work during each grantee meeting so we could see how different communities identified and engaged YMSM of color.

Although several demonstration sites experienced challenges in refining their interventions, most experienced great success, especially in the last years of the initiative, when they moved a considerable number of participants from outreach into treatment—and into care. Hidalgo continues:

There were many common lessons learned, in what was a challenging initiative for staff and researchers. We also gained considerable knowledge around designing and implementing a continuum of care for a very difficult-to-reach population. These are young people, who have different needs clinically

For More Information . . .

For additional information on the SPNS YMSM of Color Initiative, visit <http://hab.hrsa.gov/about/hab/special/youngmsmcolor.html> or <http://www.yescenter.org>, or contact

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- Jessica Xavier (301.443.0833; jxavier@hrsa.gov).

anyway, from populations who have been severely [affected] by socioeconomic and psychosocial issues.

Sustainable Results

Many of the grantees successfully moved from demonstration project to sustainable program by obtaining different funding streams, either from private funding sources or from different Parts of the Ryan White HIV/AIDS Program. In those cases, the demonstration project bolstered existing programs. As Angulique Outlaw, who ran the demonstration site at Wayne State University, explains, “The funding helped us expand activities we were already pursuing, enabling us to test additional youth and support additional staff positions. We weren’t recreating the wheel.”

Conversely, grantees unable to sustain their demonstration projects had minimal infrastructure in place and possessed little capacity to both pursue SPNS intervention activities and secure new funding to maintain them once the grant period ended. Several programs had been in operation less than 3 years prior to becoming a demonstration site and depended on demonstration project funding to support staff positions. Despite the challenges, these organizations reported that the demonstration project experience—including the organizational development and technical assistance provided by the GWU YES Center and their peers—helped bolster their overall capacity and helped them incorporate some of their initiative-related activities, albeit on a much smaller scale, after the demonstration project ended. The experience also ensured that the HIV-positive YMSM of color identified under their program remained in HIV primary care and treatment.

Recommendations for Replication

Grantees and evaluators compiled substantial data that ultimately will result in significant contributions to the literature on YMSM of color living with HIV and successful, replicable models of care. Most of the YMSM of color who participated in the initiative stayed in care; remaining in care, in turn, helped them establish steadier lives, gain more meaningful employment, enroll in health insurance, and secure stable housing.

SPNS grantees also developed a unique expertise in how to engage, serve, and retain this historically difficult-to-reach population. Their experience will play a key role in helping other Ryan White grantees, providers, and agencies replicate the models of

HIV care they developed. Some of the hallmarks of sustainability and replication reported by SPNS participants are as follows:

- In-reach is as good as outreach. Providers should look within their health records to find YMSM of color living with HIV who have fallen out of care.
- Cultural competency involves more than hiring a peer or an MSM of color; it means having someone on staff who honestly cares for YMSM of color living with HIV and their needs.
- Flexibility with program operations and the YMSM of color at risk for or living with HIV being targeted is crucial.
- Traditional face-to-face outreach, at the time of the initiative, proved more effective than high-tech communications.

Final Insights: What Does the Future Hold?

Replicating the SPNS YMSM of color models of care nationwide may be more important than ever. Epidemiological data from 2008 and 2010 indicate that the epidemic among YMSM of color shows no signs of slowing. Efforts to find additional ways to reach, engage, and retain YMSM of color in care must continue.

In the future, community involvement may play a greater role. “I think that it is really important to involve community members in your project planning, so that you are putting together a project with community support,” says Lisa Hightow-Weidman of the University of North Carolina School of Medicine. In addition to community buy-in, efforts to address and mitigate the impact of HIV/AIDS stigma will be paramount, along with employment of online outreach strategies using newer, easier-to-use social networks (e.g., Facebook) and affordable texting, smartphone, and mobile phone technologies.

The success of the YMSM of color initiative extends beyond moving clients from outreach and into care. It is about saving lives that otherwise would have been lost and building the capacity of grantees who otherwise would not have had an opportunity to reach this population. The demonstration project also has generated an enduring peer network, through which many of the YMSM of color initiative grantees continue to exchange ideas and share lessons learned. As Outlaw says,

It was a great 5 years. We are still colleagues, still working on papers, still seeing each other at conferences. We built camaraderie and amassed incredible data. We want to get that information out there, so that others can adopt what we learned and engage and recruit YMSM of color into care. There’s still more work that has to be done, and we all know that.

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