


The Transgender Women of Color Initiative: Implementing and Evaluating Innovative Interventions to Enhance Engagement and Retention in HIV Care

To improve health outcomes among transgender women of color living with HIV, the Health Resources and Services Administration's Special Programs of National Significance program funded the Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative in 2012.

Nine demonstration projects in four US urban areas implemented innovative, theory-based interventions specifically targeting transgender women of color in their jurisdictions.

An evaluation and technical assistance center was funded to evaluate the outcomes of the access to care interventions, and these findings will yield best practices and lessons learned to improve the care and treatment of transgender women of color living with HIV infection. (*Am J Public Health*. 2017;107:224–229. doi:10.2105/AJPH.2016.303582)

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 See also Landers and Kapadia, p. 205.

The literature has increasingly focused on the health of transgender people, those whose gender identities do not correspond with their sex assigned at birth.¹ Internationally and domestically, mounting evidence indicates that HIV is a concentrated epidemic among transgender people, primarily transgender women of color,² similar to that among men who have sex with men.³ The National HIV/AIDS Strategy: Updated to 2020 prioritizes successfully integrating people living with HIV into care to suppress their viral load, improve their health, and reduce their risk of transmitting HIV. Achieving an undetectable viral load requires that people living with HIV fully engage in the HIV continuum of care by learning their HIV status, linking to HIV care, staying in care over time, receiving appropriate treatment, and adhering to antiretroviral therapy. According to a 2013 Centers for Disease Control and Prevention (CDC) analysis, only an estimated 54.7% of people diagnosed with HIV in 32 states and the District of Columbia had undetectable viral loads.⁴

Although the CDC has not yet reported HIV surveillance data for transgender people (who have been classified as men who have sex with men), it published data, beginning in 2000, indicating that transgender people are at high risk for HIV/AIDS and that many may be living with HIV.^{5,6} The CDC introduced a transgender response option to its HIV testing demographics and reports that from 2008 to 2013 transgender persons had higher seropositivity rates (range = 1.7%–4.7%) than did cisgender (nontransgender) men (range = 0.9%–1.4%) and women (range = 0.2%–0.4%).⁷

Because discrete core surveillance data are not reported, much of what is known about HIV

infection among transgender persons has been gained through urban health department and community-driven needs assessment surveys and risk behavioral studies, using mostly convenience sampling. The CDC conducted a meta-analysis of these studies and estimated an HIV prevalence among transgender women of almost 12% among participants in 18 studies who self-reported their HIV status.⁸ However, the estimated HIV prevalence among those tested in four studies was nearly 28%, suggesting that 45% to 65% of transgender women living with HIV are unaware of their HIV status. This places about half of transgender women living with HIV among the 13% of persons living with undiagnosed HIV infection in the CDC's most recent

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estimates.⁹ In previous research, African American and Latina transgender women were found to have the highest HIV prevalence rates: as high as 63%¹⁰ and 50%,¹¹ respectively. Furthermore, young transgender women of color may be particularly vulnerable to HIV infection.¹²

Despite the high rates of HIV prevalence and risk behaviors research has identified, there is increasing evidence of treatment disparities among transgender women living with HIV/AIDS. According to 2014 data from the Ryan White HIV/AIDS Program (RWHAP), only 5567 transgender persons nationwide received RWHAP services, with the majority (88%) being transgender women.¹³

Although retention in HIV care for transgender adults and adolescents receiving RWHAP services was close to the national program average (78.4% vs 80.4%) viral suppression among transgender people living with HIV was lower than was the national RWHAP average (74.0% vs 81.4%). It should be noted that people living with HIV who receive care from RWHAP-funded providers have better health outcomes than national estimates.

There is also considerable evidence that transgender people experience barriers when attempting to access health care, including discrimination by health care providers who have denied medical care to transgender people.¹⁴ Past experiences with provider insensitivity and hostility can produce an intense fear of disclosing transgender status, causing many to avoid the health care system.¹⁴ High rates of joblessness and poverty among transgender people, especially those of color and transgender youths, often result in a lack of health insurance or in underinsurance.¹⁴ Taken together, these factors present potent

barriers to access of all forms of health care, including HIV primary care for those living with HIV.

Accordingly, in 2005, the Health Resources and Services Administration's HIV/AIDS Bureau convened a community consultation meeting on transgender people living with HIV.¹⁵ The consultation's recommendations included better education, especially for medical providers and Health Resources and Services Administration-funded recipients; improvements in epidemiological and service utilization data to better reflect the high levels of HIV in the transgender population; and improved access to transgender-specific resources such as mental health and hormonal therapy providers. The participants also called for the funding of a Special Projects of National Significance (SPNS) demonstration project initiative that would target transgender populations and treatment interventions. The Health Resources and Services Administration responded to this last recommendation in 2012 by funding nine demonstration projects in four urban centers in the SPNS initiative titled Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color. An evaluation and technical assistance center cooperative agreement was awarded to the Center for AIDS Prevention Studies at the University of California, San Francisco. The Center for AIDS Prevention Studies teamed with the Center of Excellence for Transgender Health to provide technical assistance to the demonstration projects and to conduct a multisite evaluation.

The nine demonstration projects were conducted at community (n = 4) and clinical (n = 5) sites. There were many commonalities among the

interventions. Table 1 shows the intervention mix of all activities at each site, including interventions funded by SPNS, interventions not funded by SPNS, and referrals offered to other services. The SPNS-funded interventions were not intended to be stand-alone interventions and were meant to "float" on top of an organization's existing structure and programs. Some of the intervention activities were completely new additions to a demonstration site's current programming, and some resulted in an agency implementing more intensive programming than was previously offered.

All sites employed one or more theories that served as a foundation for intervention development and implementation, considering the unique experiences of transgender women of color in their jurisdictions. Many sites grounded their interventions in social cognitive theory,¹⁶ social learning theory,¹⁷ or the trans-theoretical model of behavior change.¹⁸ Other interventions were rooted in theories of gender and power,¹⁹ syndemic theories,²⁰ or critical race theory.²¹ Other philosophies that guided interventions included motivational enhancement,²² behavioral economics,²³ the patient-centered medical home model,²⁴ and strength-based service provision.²⁵

The demonstration sites developed and implemented innovative interventions to specifically address these health disparities. Table 2 illustrates the specific intervention activities that sites adopted and the HIV continuum of care stage addressed by each activity. For example, one of the most common intervention activities was community outreach. Sites' community outreach activities

typically addressed the identification and linkage stages, but one site also promoted antiretroviral therapy adherence via outreach activities. Typically, the interventions included three key elements: (1) culturally competent services, including linkages, referrals, advocacy, provision of HIV care, and hormones; social and emotional support; health education; and access and referrals to address unmet immediate needs; (2) supportive messages that contribute to health literacy and personal and community development; and (3) increased social support, which was achieved by cultivating caring relationships and interactions between staff and transgender women of color, among intervention participants, and between transgender women in the interventions (taking on roles of advocates and educators) and positive peers in their communities not receiving HIV care.

INTERVENTIONS AT COMMUNITY SITES

The SPNS initiative funded four demonstration sites at community agencies that do not provide direct medical services. These sites partnered with local clinics to provide gender-affirming and HIV-related health care.

BIENESTAR Human Services, Los Angeles

BIENESTAR is an organization serving the Latino community in Los Angeles County, California. Funding from the SPNS initiative allowed BIENESTAR to develop a new program, TransActivate, which includes multiple activities to improve engagement in HIV

TABLE 1—Intervention Activities Offered by Each Agency: Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative, Unites States, 2012

Activity	BHS	CH	CHN	FRI	HBH	PHI	SFDPH	SUNY	TCHC
Community outreach	1	1	1, 2	2	1, 2	1, 2	1, 2	1, 2	1, 2
Navigation	1	1	1, 2	1	1, 2	1	1, 2	1, 2	2
Small groups	2		1	2	1, 2	1, 2	1, 2	1	1
Other individual sessions ^a	2		1, 2	2		1, 2	1, 2	1, 2	1, 2
Drop-in center	2	1, 2	2	2	1, 2	1, 2	1, 2		
Trans-related health care (non-HIV)	3	3	1, 2, 3	3	1, 2	3	1, 2	1, 2	2
Case management or social work	3	2	1, 2		2	3	1, 2	1, 2	2
HIV testing	2	2	1, 2	2	1, 2	3	2	1, 2	2
Transcompetent HIV medical care	3	3	1, 2, 3	3	2	3	1, 2	1, 2	2
Community advisory board		1, 2	1, 2					1, 2	
Social network engagement	1		1	1		1			
Motivational interviewing	1					1			
Onsite health education with limited medical care		1							
Contingency management				1					
Transcompetency trainings	3	1	2		2, 3	2	2	2	
Social network recruitment				1					

Note. 1 = activity funded by the SPNS initiative; 2 = activity offered onsite but not funded by the SPNS initiative; 3 = referrals offered to this activity. BHS = BIENESTAR Human Services (TransActivate); CH = Chicago House & Social Services (Trans Life Center); CHN = Community Healthcare Network (T.W.E.E.T. [Transgender Women Entry and Engagement To] Care Project); FRI = Friends Research Institute (Alexis Project); HBH = Howard Brown Health (After Hours); PHI = Public Health Institute (Princess Project); SFDPH = San Francisco Department of Public Health (Trans Access); SPNS = Special Projects of National Significance; SUNY = State University of New York Downstate Medical Center (INFINI-T); TCHC = Tri-City Health Center (Brandy Martell Project).

^aOther individual sessions do not include navigation, case management, or social work sessions.

care for transgender women of color living with HIV.

TransActivate uses peer navigation to facilitate engagement in health care services by accompanying participants to medical appointments, addressing barriers to engagement in care, modeling behavior in interacting with medical staff, increasing knowledge related to behaviors affecting health, and providing referrals for services to help participants address life challenges. TransActivate also includes outreach and uses the social networks of Latina transgender women for recruiting program participants.

Chicago House, Chicago, IL

Chicago House is a social service agency that serves

individuals and families who are disenfranchised by HIV/AIDS; lesbian-, gay-, bisexual-, or transgender-associated marginalization; poverty; homelessness; or gender nonconformity. Chicago House developed a new program called the TransLife Center, which conducts community outreach and provides a transgender-affirming environment and programming to address the social and structural determinants of health.

A drop-in center provides transgender-affirming space where transidentified and gender nonconforming individuals can find social support and a safe harassment-free space as well as direct access to housing resources, legal services, employment services, and transgender-affirming

health education and linkage to medical care. The program also conducts transcultural competency provider training for a broad network of social service and medical providers.

Friends Research Institute, Los Angeles

Friends Community Center is Friends Research Institute’s community research site in Los Angeles, and it provides services for and conducts research with substance-using gay and bisexual men, other men who have sex with men, and high-risk transgender women. Funding from the SPNS initiative allowed Friends Research Institute to develop a new program called the Alexis Project. The Alexis Project uses social network

recruiting to identify and test high-risk transgender women of color (TWOC) who are HIV infected but unaware of their HIV status.

Additionally, social network engagement identifies TWOC who are aware of their HIV infection but have never been in care or are antiretroviral therapy medication nonadherent. The Alexis Project includes a peer health navigation intervention coupled with contingency management to provide increasingly valuable incentives (e.g., gift cards) for attending HIV medical visits and reaching and sustaining HIV milestones.

Public Health Institute, Oakland, CA

The Public Health Institute is dedicated to promoting health, well-being, and quality of life for people in California and elsewhere. Through the SPNS initiative, the Public Health Institute’s project team developed a new program, called the Princess Project. Transgender health educators work with African American transgender women living with HIV to clarify individual needs, set up attainable goals for behavioral change, and motivate clients to attain the goals.

Clients receive motivational enhancement intervention sessions, and the project offers community outreach and inreach and weekly support groups at a safe space (the Butterfly Nest) in Oakland, where clients can build a supportive social network and participate in health promotion workshops.

INTERVENTIONS AT CLINICAL SITES

The SPNS initiative also funded five demonstration sites

TABLE 2—Number of Demonstration Sites Offering Specific Intervention Activities and Each Activity's Relationship to the HIV Continuum of Care: Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative, United States, 2012

Activity	No. Sites Offering Services Onsite or by Referral	HIV Care Continuum Stage Addressed by Each Activity ^a			
		Identification	Linkage	Retention	Antiretroviral Therapy Adherence
Community outreach	9	8	8		1
Navigation	9		9	9	8
Transrelated health care (non-HIV)	9	2	7	6	5
Transcompetent HIV medical care	9		4	7	8
HIV testing	9	8	6		
Case management and social work	8	1	5	6	4
Small groups	8	2	3	5	3
Other individual sessions ^b	7	1	6	6	6
Drop-in center	7	5	6	4	2
Transcompetency trainings	7	2	1	5	3
Social network engagement	4	1	1	1	1
Community advisory board	3	1	1	2	1
Motivational interviewing	2		2	2	2
Onsite health education with limited medical care	1			1	
Contingency management	1		1	1	1
Social network recruitment	1	1			

^aSome activities address multiple care continuum stages.

^bNot navigation or social work sessions.

at agencies that provide direct medical care in addition to a variety of other support services designed to improve engagement in HIV-related health care.

Community Healthcare Network, Queens, NY

Community Healthcare Network provides culturally competent and comprehensive community-based primary care as well as mental health and social services for diverse populations in underserved communities throughout New York City. Funding from the SPNS initiative allowed Community Healthcare Network to create the T.W.E.E.T. (Transgender Women Entry and Engagement To) Care Project.

The T.W.E.E.T. Care Project mobilizes peer leaders to conduct outreach and to engage and link TWOC living with HIV who are newly diagnosed or lost to care by conducting “teach backs.” In these sessions, transgender women teach each other HIV prevention, care, and treatment basics and then share what they learn in their social networks.

Howard Brown Health, Chicago

Howard Brown Health is a federally qualified health center that provides comprehensive primary medical and behavioral health care and ancillary services to the lesbian, gay, bisexual, and transgender community. Funding from the SPNS initiative allowed Howard Brown Health

to launch a twice monthly evening drop-in clinic, called After Hours, for transgender and gender nonconforming people. After Hours includes walk-in access to primary medical and behavioral health care, hormone therapy, sexual health and sexually transmitted infection testing and treatment, linkage to HIV care, case management and resource advocacy, and a trans-only community space.

Additionally, Howard Brown Health developed a trans-specific outreach program and strengthened two ongoing support groups. The SPNS-funded program also included an agency-wide initiative to assess and improve trans-affirmative care and revised Howard Brown Health's hormone therapy protocol to provide greater access.

Department of Public Health, San Francisco

The San Francisco, California, Department of Public Health is a local health department that provides a comprehensive primary care medical home tailored to the needs of low-income transgender persons. Funding from the SPNS initiative allowed the San Francisco Department of Public Health to partner with a local community-based organization to create the Trans Access Program. This project was designed to augment existing support groups and other services at a local transgender drop-in center and a transgender community mobilization HIV testing effort.

Trans Access provides weekly transgender and HIV primary care medical services at the community-based organization in a welcoming environment with an established transgender community footprint and credibility. The project also offers peer navigation services in addition to other comprehensive wraparound services. Additionally, Trans Access conducts community outreach, linkage to care services, and a transgender leadership and speakers bureau.

SUNY Downstate, Brooklyn, NY

Health & Education Alternatives for Teens provides comprehensive HIV treatment to transgender youths living with HIV by an interdisciplinary team. SPNS funding allowed Health & Education Alternatives for Teens to develop a new program, INFINI-T, to attract and retain young TWOC living with HIV using a youth-focused “one-stop shop” model.

INFINI-T addresses multiple psychosocial factors that

transgender youths of color living with HIV face in their daily lives. Services provided at INFINI-T include improved outreach to and engagement of young transgender women at a local lesbian, gay, bisexual, and transgender community-based organization; colocated HIV and transgender medical care; dedicated social work services; enhanced mental health services and psychological testing; a transgender youths of color community advisory board to guide INFINI-T; and a group-level intervention that uses peer role modeling to improve self-image, increase life skills, and reduce risks.

Tri-City Health Center, Fremont, CA

Tri-City Health Center offers comprehensive transgender health care and provides a wide spectrum of health-related services. SPNS funding allowed Tri-City Health Center to develop a new program called the Brandy Martell Project (BMP). The focus of BMP is to serve African American and Latina transgender women living with HIV who reside in Alameda County, California, and neighboring counties. BMP provides a legal clinic with an attorney who works with clients to address legal issues affecting their ability to engage in HIV care and maintain treatment adherence.

BMP also offers Living Real sessions that include life skills building, HIV treatment, legal rights, transgender history, and transgender health care workshops. The workshops also connect clients to professional skills training, internships, mentors, and job placement. Additionally, BMP facilitates health care enrollment at

Tri-City Health Center or another clinic.

CONCLUSIONS

Through the SPNS demonstration project initiative to enhance engagement with and retention in quality HIV care for TWOC, the Health Resources and Services Administration emphasized the three primary objectives outlined in the original US National HIV/AIDS Strategy: to reduce new infections, to increase access to care and improve health outcomes for people living with HIV, and to reduce HIV-related health disparities and health inequities. The HIV epidemic among TWOC is a prime example of HIV-related health disparities caused by a complex intersection of multiple stigmas (e.g., transphobia, racism, sexism, HIV, sex work); substance use; recurrent incarceration and victimization in the criminal justice system; homelessness and marginal housing; relationship and other forms of violence; institutional inattention, indifference, and mistreatment; mental health issues; lack of economic opportunities; and other challenges.

Reports on the findings, best practices discovered, and lessons learned from this initiative to improve linkage and retention in HIV primary care for TWOC are expected to begin in 2017, and they will serve to inform future policy and practice for programs working in transgender communities of color. Successful scale-up of the interventions will take high levels of commitment, enthusiasm, patience, persistence, and expertise to work through all the cooccurring barriers to health care engagement so we can effectively engage TWOC living with HIV

with high-quality, culturally competent HIV primary care. *AJPH*

CONTRIBUTORS

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HUMAN PARTICIPANT PROTECTION

This project was approved by nine institutional review boards, including those of the University of California, San Francisco (UCSF) and all demonstration sites (except Tri-City Health Center, which designated UCSF as their institutional review board of record).

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