



# What's Going on @ SPNS



AN UPDATE FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTH RESOURCES AND SERVICES ADMINISTRATION,  
HIV/AIDS BUREAU, SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

JANUARY 2012

## ■ Improving Linkages and Access to Care

According to estimates from the U.S. Centers for Disease Control and Prevention (CDC), approximately 50,000 new HIV infections occur each year,<sup>1,2</sup> and an estimated 21 percent of infected persons are unaware of their serostatus.<sup>3</sup> The highest prevalence is in urban areas, where many people infected with or at high risk for HIV reside. In several major U.S. cities, seroprevalence rates exceed the 1 percent threshold that constitutes an epidemic. In Washington, DC, for example, 3 percent of residents are infected.<sup>4</sup> Seroprevalence rates among certain populations are even higher: African-Americans, Latinos, and men who have sex with men in particular have been hard hit by HIV/AIDS and represent “hard-to-reach” populations.<sup>5,6</sup> In some cases, entire States bear the disproportionate burden of HIV disease.<sup>2</sup>

People unaware of their serostatus are more likely to engage in risky health behaviors such as unprotected sex.<sup>7</sup> In fact, people living with HIV/AIDS (PLWHA) who are unaware of their status account for more than one-half of new infections.<sup>8</sup> Conversely, when people know their HIV status, they are less likely to pass on the disease, and studies show that patients on antiretroviral therapy (ART) are, in fact, less infectious.<sup>6</sup>

Lack of awareness can lead to advanced HIV disease: 35 to 45 percent of people with newly diagnosed HIV infection develop AIDS within 1 year after diagnosis, representing late entry into care. PLWHA who enter care at this point often have extremely compromised immune systems and AIDS-related complications.<sup>6</sup> These data underscore the need to more readily

- identify those with undiagnosed HIV,
- link persons who have tested positive for HIV into care,
- reconnect PLWHA who have dropped out of care, and
- retain patients in quality HIV care services (including access and adherence to ART).

A new Special Projects of National Significance (SPNS) initiative seeks to achieve those goals.

### **Efforts to Increase HIV Testing and Linkage to Care**

Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative (the Systems Linkages initiative) is an effort funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). The initiative funds seven Part B (States/U.S. Territories) Ryan White HIV/AIDS Program grantees for up to 4 years (2011–2015); the objective is to develop innovative and replicable systemic models of care. The initiative aims to improve linkages of PLWHA to necessary testing, treatment, and care services and is reflective of SPNS’ ability to evolve as the epidemic warrants and address increasing needs. This project in particular will have extensive reach and powerful implications as Demonstration States create and test models that could one day be implemented on a national scale.

Efforts to increase testing, however, are nothing new. In 2006, the CDC released testing recommendations seeking wider scale HIV testing (including screening for people ages 13 to 64 in all health settings),<sup>9,10</sup> and the Ryan White HIV/AIDS Treatment Extension Act of 2009 directed Part A and B grantees to seek early identification of PLWHA unaware of their status and link them to care.

HRSA’s AIDS Education and Training Centers offer technical assistance trainings to expand HIV testing and counseling in medical care settings and have reached more than 50,000 providers and conducted more than 3,100 trainings on Federal testing guidelines. Thanks in part to these trainings, more than 500 sites have implemented routine testing.<sup>11</sup> HRSA’s Bureau of Primary Health Care providers, who serve nearly 19 million patients in the Nation’s neediest communities, are also working toward the goal of increased testing.<sup>12</sup>

The relatively stable but high HIV incidence, however, calls for new strategies, including broader, more coordinated efforts across health care systems. To achieve this target, the 2011 Part B application guidance required grantees to describe their plans for addressing unmet needs for HIV-related services for PLWHA unaware of their status, and it required that grantees outline the steps they will take to implement those plans. To support Part B grantees in States heavily affected by HIV/AIDS, the System Linkages initiative will offer a new kind of capacity-building and shared-learning environment in which States will further integrate different components of their public health systems to work as one seamless unit.

“We’re not just going to have demonstration sites,” says Jessica Xavier, SPNS project officer, “but Demonstration States. So we’re not asking a single provider to implement these strategies, but entire States seeking to involve all of their HIV services organizations, along with some non-traditional organizations who can get involved in testing and referral to care.” Nontraditional organizations include community health centers, substance abuse clinics, mental health providers, hospitals, and outpatient medical clinics, all of whom, Xavier says, “have not traditionally had an HIV focus or done extensive HIV testing.”

Concurrently, the CDC is exploring complementary efforts at the city level with its Enhanced Comprehensive HIV Prevention Planning (ECHPP) Project ([www.cdc.gov/hiv/strategy/echpp/index.htm](http://www.cdc.gov/hiv/strategy/echpp/index.htm)) in the 12 U.S. cities with the highest HIV prevalence. As Xavier explains, “CDC is focusing on cities, but it is also necessary to improve the coordination of services at the State level. That’s where HAB is filling the void, and this is all, of course, driven by the National HIV/AIDS Strategy.”

## The System Linkages Initiative and the National HIV/AIDS Strategy

The National HIV/AIDS Strategy, created by the White House Office of National AIDS Policy in collaboration with other Federal partners, calls for a combination of effective, evidence-based approaches along with targeted efforts and funding to populations and areas most in need. Achieving these ambitious goals requires strengthening HIV screening and surveillance activities and improving upon surveillance methods. It also necessitates the establishment of a seamless, continuous, and coordinated system that facilitates immediate linkages to care upon HIV diagnosis and strengthened retention efforts to better maintain patients in HIV primary care services.<sup>13</sup>

To best achieve the goals of the Systems Linkages initiative, grantees will be focusing on people unaware of their HIV status, defined as “any individual who has not been tested for HIV in the past 12 months, or any individual who has not been informed of their HIV test result (HIV positive or HIV negative), or any HIV positive individual who has not been informed of their confirmatory HIV test result.”<sup>14</sup> Outreach to and engagement with people who do

## For More Information . . .

The SPNS staff and project officers working on the System Linkages initiative are

- Adan Cajina (301.443.3180; [acajina@hrsa.gov](mailto:acajina@hrsa.gov)),
- Pamela Belton (301.443.4461; [pbelton@hrsa.gov](mailto:pbelton@hrsa.gov)),
- Katherine Godesky (301.443.7874; [vgodesky@hrsa.gov](mailto:vgodesky@hrsa.gov)),
- Melinda Tinsley (301.443.3496; [mtinsley1@hrsa.gov](mailto:mtinsley1@hrsa.gov)), and
- Jessica Xavier (301.443.0833; [jxavier@hrsa.gov](mailto:jxavier@hrsa.gov)).

not know their HIV status are critical to the effort of curtailing HIV infections in our country.

As the care continuum in Figure 1 illustrates, PLWHA may move from being fully engaged in care to sporadically or completely out of care; thus, efforts in this initiative also involve bringing patients back into care and keeping their viral load suppressed through the use of antiretroviral medications. “SPNS is always looking to identify innovative strategies, especially with the specific needs of the most affected subpopulations,” explains Katherine Godesky, SPNS project officer. So although this particular initiative is SPNS’ first statewide effort, Godesky says, “it didn’t really change what SPNS is all about. . . Part B grantees, however, have further reach so they can institute, replicate, and grow these interventions much further than what we’ve seen before.”

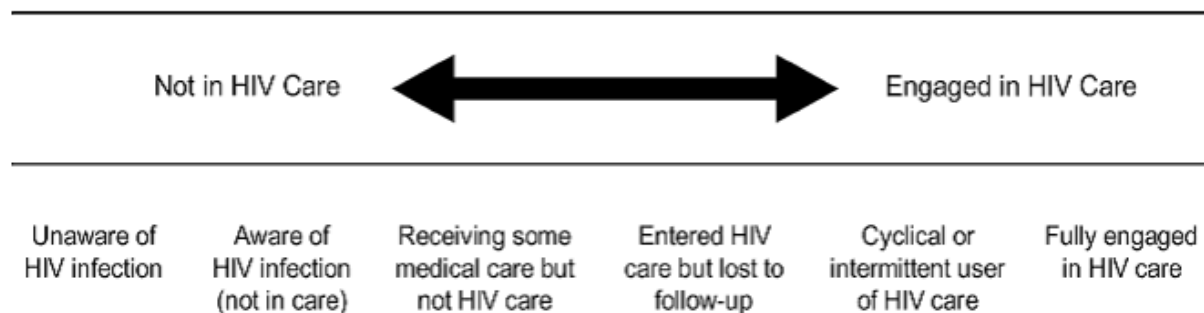
## Removing Barriers, Improving Care

The Institute of Medicine classifies barriers to accessing care into three categories: structural, financial, and personal/cultural.<sup>15</sup> SPNS has focused on these barriers previously and identified ways to overcome them and successfully link to and retain hard-to-reach populations in HIV primary care.<sup>16</sup> Where the Systems Linkages initiative differentiates itself is in applying lessons learned in a broad, State-level, cross-agency coordinated fashion.

As such, Demonstration States have to develop strategies to overcome structural barriers to accessing care, and they must leverage their existing funding and resources to work with key partners and stakeholders to integrate different components of their State’s public health system. These efforts will require sharing data to more accurately identify the number of new HIV cases in their area; assessing where target populations are located; and aggressively conducting HIV counseling, testing, and linkage to care for those populations.

To accomplish these goals, Demonstration States will adopt the Institute for Healthcare Improvement (IHI) Collaborative Model, which uses a team-based approach led by content experts. The experts serve as “faculty” and help organizations implement smaller scale changes, adapting or modifying as necessary, and

**Figure 1. Engagement in Care Continuum**



Source: HRSA. Outreach: engaging people in HIV care: summary of a HRSA/HAB 2005 consultation on linking PLWH into care. August 2006.

then slowly rolling out successful changes on a larger scale. This pilot-testing approach is known as “Plan-Do-Study-Act” (PDSA).

The Collaborative Model has been proven successful across other HRSA initiatives, and it allows grantees to make changes and test strategies in the planning phase before full adaptation across the State. “This is the first time SPNS is using the IHI model,” says Xavier, “but HAB has used this model previously for Title I [Part A] and Title III [Part C] and, most recently, in the cross-Part Quality Management collaborative efforts. This model has had traction and success, so we were asked to see if we could make these kinds of system-level partnerships work within a State.” Other selling points for the model include a focus on the necessary quality improvement strategies for testing and surveillance data.

To ensure success, the initiative’s evaluation center will offer technical and capacity-building assistance to Demonstration States throughout the course of the project. “We change from identifying small-scale interventions in Years 1 and 2,” says Godesky, “to expanding in Years 3 and 4 across the State.” In this way, Years 1 and 2 allow a kind of pilot project to identify any challenges, make adjustments, and re-execute launch before statewide rollout.

“The evaluation center will be conducting a lot of trainings throughout the initiative on PDSA cycle, counseling and testing, engagement and retention strategies, quality improvement, and capacity building,” adds Godesky. “The hope,” she says, “is that successful States will serve as a model for others. This initiative involves two States with cities participating in the CDC 12 Cities project, so it’s important for us to work closely with the CDC on this, as well.”

Godesky explains that it’s not just Federal agencies that must work together but all entities, large and small, in order to achieve all that the initiative sets out to do. “A lot of organizations work in silos,” explains Godesky, “and now we’re asking them to work to-

gether in their communities and across the State, representing an important and exciting time in public health.”

“Strengthening collaboration among Ryan White-funded grantees and providers is a long sought-after goal of HAB, and we do recognize that at a time when resources are increasingly limited, these kinds of partnerships are more important than ever before,” adds Xavier. “This initiative will create better care coordination and produce replicable models that will hopefully foster adaptations among other States not involved in the study.”

Looking ahead, Xavier says, “I think this initiative is representative of what’s to come: all Federal agencies moving forward to what’s outlined in the National HIV/AIDS Strategy and coming together to collaborate more frequently.” The end result? Curtailing HIV infections across the country and, ultimately, healthier Americans.

## Endnotes

- 1 Prejean J, Song R, Hernandez A, et al. Estimated HIV incidence in the United States, 2006–2009. *PLoS ONE*. 2011;6(8):e17502.
- 2 U.S. Centers for Disease Control and Prevention (CDC). *HIV Surveillance Report*. 2009;21:Tables 20 and 21. Available at: [www.cdc.gov/hiv/topics/surveillance/resources/reports/](http://www.cdc.gov/hiv/topics/surveillance/resources/reports/). Accessed August 2, 2011.
- 3 CDC. *HIV in the United States*. 2010. Available at: [www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf](http://www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf). Accessed July 1, 2011.
- 4 Vargas JA, Fears D. At least 3 percent of DC residents have HIV or AIDS city study finds; rate up 22% from 2006. *Washington Post*, March 15, 2009. Available at: [www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176.html](http://www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176.html). Accessed September 2, 2011.
- 5 Harris HR. District notebook. *Washington Post*, March 19, 2009. Available at: [www.washingtonpost.com/wp-dyn/content/article/2009/03/18/AR2009031801337.html](http://www.washingtonpost.com/wp-dyn/content/article/2009/03/18/AR2009031801337.html). Accessed September 2, 2011.
- 6 Gardner E, McLees M, Steiner J, et al. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies

- for prevention of HIV Infection. *Clin Infect Dis*. 2011;52:793-800.
- 7 Marks G, Crepaz N, Senterfit JW, et al. Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: Implications for HIV prevention programs. *J Acquir Immune Defic Syndr*. 2005;39:446–53.
  - 8 Marks G, Crepaz N, Janssen RS. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *AIDS*. 2006;20:1447–5014.
  - 9 Branson B, Handsfield H, Lampe M, et al. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *MMWR*. 2006;55(RR14):1–17.
  - 10 CDC. *HIV/AIDS science facts: CDC releases revised HIV testing recommendations in health care settings*. 2006. Available at: [www.cdc.gov/hiv/topics/testing/resources/factsheets/health-care.htm](http://www.cdc.gov/hiv/topics/testing/resources/factsheets/health-care.htm). Accessed July 1, 2011.
  - 11 Health Resources and Services Administration (HRSA). *HIV testing: linking unaware into care*. n.d. Available at: [http://careacttarget.org/feature/hiv\\_testing\\_linking\\_unaware\\_into\\_care.asp](http://careacttarget.org/feature/hiv_testing_linking_unaware_into_care.asp). Accessed May 6, 2011.
  - 12 Bureau of Primary Health Care. *HIV testing in health care settings*. Program Assistance Letter No. 2010-13. Available at: <http://bphc.hrsa.gov/policy/pal1013/pal1013.pdf>
  - 13 White House Office of National AIDS Policy. *National HIV/AIDS Strategy*. 2010; p. 23. Available at: [www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf](http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf). Accessed September 6, 2011.
  - 14 HRSA. *Systems linkages and care initiative to high risk populations demonstration sites*. 2011. Available at: <https://grants.hrsa.gov/webExternal/FundingOppDetails.asp?FundingCycleId=1C92B998-7D33-4F07-8B04-AF536D1A657A&ViewMode=EU&GoBack=&PrintMode=&OnlineAvailabilityFlag=&pageNumber=&version=&NC=&Popup=>. Accessed May 6, 2011.
  - 15 Institute of Medicine. *Access to health care in America*. Washington, DC: National Academies Press; 1993. Available from: [www.nap.edu/catalog.php?record\\_id=2009](http://www.nap.edu/catalog.php?record_id=2009). Accessed September 22, 2011.
  - 16 HRSA. *SPNS—Special Projects of National Significance (Part F)*. n.d. Available at: <http://hab.hrsa.gov/abouthab/partfspns.html>. Accessed September 6, 2011.