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Linkage to Care: Strengthening the HIV Care Continuum in Wisconsin

Leslie Anderson, Kathleen Krchnavek, Mari Ruetten, Casey Schumann, James Stodola, AIDS/HIV Program, Division of Public Health, Wisconsin Department of Health Services

Introduction

This issue of *Program Notes* highlights new HIV linkage to care initiatives in Wisconsin and provides an overview of linkage to care and the key role that it serves in improving health outcomes and curbing the transmission of HIV.

What is linkage to care?

The term "linkage to care" is broadly defined as connecting HIV-infected individuals to HIV care and treatment services for the first time. This differs from "retention in care" in that linkage applies only to individuals new to care. Retention in care refers to services and systems that help HIV infected individuals remain engaged in care and treatment services, including support services that assist clients in adhering to treatment plans and therapies.

The *National HIV/AIDS Strategy* (*NAS*),¹ released in July 2010, emphasizes the importance of improving systematic linkages to care for people living with HIV in order to improve individual health outcomes and decrease the number of new HIV infections. The *NAS* points out that a critical step in increasing access to care and improving health outcomes is to "…establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV." This requires strengthening initial linkages to care and providing systematic retention support to those with long-standing HIV infection.

Figure 1 illustrates the continuum of engagement in care, from being unaware of infection to being fully engaged in care. This framework can assist providers in identifying service gaps and improving the continuum of care in order to achieve optimal treatment outcomes.²



Figure 1. Spectrum of patient engagement in HIV care

Over the past decade, several studies demonstrated that continued suppression of HIV viral loads through effective, widespread use of antiretroviral therapy contributes significantly to curbing

¹ National HIV/AIDS Strategy for the United States. July 2010. Available from <u>http://www.cdc.gov/hiv/strategy/pdf/nhas.pdf</u>.

² Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical Infectious Diseases 2011;52: 793–800.

the transmission of HIV.³ The goal for systems of HIV care is to move individuals along the spectrum of engagement from being unaware of HIV infection to being fully engaged in care.

The federal Centers for Disease Control and Prevention (CDC) estimates that approximately 20% (n=240,000) of all HIV infected individuals are currently unaware of their status. Of those who are aware of their status, 49% (n= 460,000) are not retained in regular HIV care (defined as two HIV related medical visits over a 12 month period). Overall, 700,000 individuals infected with HIV are not engaged in ongoing care and, as a result, experience limited access to antiretroviral therapy. It is well documented that HIV infected individuals who are adherent to treatment and have a suppressed viral load are far less likely to transmit HIV. It is of great concern that only 28% of individuals living with HIV have a suppressed viral load.⁴



Figure 2: Number and percentage of HIV-infected individuals engaged in selected stages of the continuum of HIV care--United States

CDC defines "late testers" as persons who develop AIDS within one year of their initial HIV diagnosis and persons who are diagnosed AIDS at the same time they are diagnosed with HIV disease. In 2010, late testers accounted for 27.6% of new diagnoses as compared with 34.7% in 2006 (Figure 3). Three years after initial diagnosis, two-thirds of persons diagnosed in Wisconsin progressed to AIDS. Late testers, who are unaware of their HIV infection, are less likely to engage in risk reduction behaviors that prevent transmission of HIV.⁵ Late testers are often initially diagnosed with HIV infection only after their HIV disease has progressed. Typically,

³ Cohen MS, Gay CL. Treatment to prevention transmission of HIV-1. Clinical Infectious Diseases 2010;50: S85-S95.

⁴ Centers for Disease Control and Prevention. Vital signs: HIV Prevention through care and treatment — United States. Morbidity and Mortality Weekly Report (MMRW) 2011; Vol. 60; No. 47:1618–1623. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a4.htm?s_cid=mm6047a4_w.

⁵ Centers for Disease Control and Prevention. CDC's HIV prevention progress in the United States. July 2010. Available from <u>http://www.cdc.gov/hiv/resources/factsheets/cdcprev.htm</u>

they are sicker than persons who are diagnosed earlier and engaged in treatment. Identifying individuals earlier in their infection not only will result in improved health outcomes for individuals living with HIV but will also decrease the risk of forward transmission.





Federal project of national significance for systems linkages and access to care

In early 2011, the federal Health Resources and Services Administration released a competitive application for states to participate in a linkage to care special project of national significance (SPNS) to improve access and retention in quality care and treatment services. SPNS interventions are targeting hard-to-reach populations, including those who are unaware of HIV infection, have never been in care, or have dropped out of care.

Wisconsin is one of seven demonstration sites participating in this four-year SPNS and is currently piloting interventions among several high-risk groups, including young Black men who have sex with men (YBMSM). The primary interventions associated with this initiative are described below.

Acute HIV screening

As part of the initial SPNS application, the Wisconsin AIDS/HIV Program developed an HIV testing protocol to identify acute HIV infection (AHI) among MSM at high volume, publicly funded testing sites. AHI is a highly infectious phase of HIV disease that typically occurs 1-4 weeks after infection and lasts a few days to 4 weeks. It is characterized by nonspecific clinical symptoms often mimicking infectious mononucleosis, influenza, or other viral illnesses.⁶

Persons with AHI have a higher risk of transmitting HIV due to high levels of viremia (high viral loads) for up to 12 weeks following initial infection, a period when infection may be undetectable with traditional antibody tests. In 2010, the federal Food and Drug Administration

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5846a3.htm?s cid=mm5846a3 e.

^{*}Includes those concurrently diagnosed with HIV and AIDS

⁶ Centers for Disease Control and Prevention. Acute HIV Infection—New York City, 2008. Morbidity and Mortality Weekly Report (MMWR) 2009; 58(46);1296-1299. Available from

approved a new screening test for HIV that identifies HIV antibody as well as HIV antigen, which is a component of the virus. When used for screening, the HIV antigen/antibody (Ag/Ab) test detects infection much earlier than traditional antibody tests, reducing the window period from 3 months to 1 month after infection. Many infected individuals can receive a positive test result on an Ag/Ab test as early as 15 days after exposure.

Providers in emergency departments, urgent care centers, and community health centers should be aware of AHI symptoms and screen for HIV infection when persons report AHI symptoms and HIV risk behaviors. The CDC will be revising the standard HIV testing algorithm this year to incorporate the Ag/Ab test as the initial screening test for HIV infection in order to capture individuals who may be in the acute stage of HIV infection.

Expansion of Partner Services

HIV Partner Services (PS) assist persons recently diagnosed with HIV infection and their sexual and drug-using partners. PS are coordinated by the Division of Public Health and provided by specially trained staff in local health departments. Services include HIV prevention education and counseling; assistance with notifying sexual and drug using partners of their risk exposures; HIV testing of sexual and drug-injection partners; and assessment, referral and service linkage for health and other related services. PS staff verify whether persons newly diagnosed with HIV infection are engaged in HIV care services and, if not engaged, staff provide a referral and conduct referral follow-up to ensure a successful linkage to an HIV care provider. As part of the SPNS initiative, several PS agencies are piloting expanded PS, which involves PS staff providing linkage assistance and conducting follow-up on two clinical visits, rather than one, before initial linkage is considered successful.

Expansion of social networks strategy testing

Social networks (SNS) testing is a strategy that delivers HIV testing by recruiting members of social networks that include persons with HIV infection or persons with HIV-related high risk behaviors. The strategy recognizes that individuals are part of social networks and that infectious diseases often spread through these networks. It is a peer-driven, recruitment strategy to reach the highest risk persons who may be infected with HIV but are unaware of their status. This is accomplished by enlisting newly and previously diagnosed HIV-positive and high-risk HIV negative recruiters on an ongoing basis and providing HIV testing to people in their networks.⁷ In Wisconsin, this testing strategy was introduced in 2008. Prevalence of new HIV cases identified using SNS testing is 1.8% versus 0.8% among traditional tests. The prevalence of new cases identified using SNS versus traditional testing strategies increases among certain high risk groups. Among African American men who have sex with men 29 years of age or younger, the primary target audience for the linkage to care initiative, the HIV prevalence using SNS is 11.5% compared to 5% for traditional testing methods.

⁷ Centers for Disease Control and Prevention. Social networks testing: a community-based strategy for identifying persons with undiagnosed HIV infection. Interim guide for HIV counseling, testing, and referral programs. Available from <u>http://www.cdc.gov/hiv/resources/guidelines/snt/pdf/SocialNetworks.pdf</u>.

Linkage to care specialists

Intensive linkage to care programs have successfully identified and retained HIV positive members of racial and ethnic minorities in HIV care and treatment services.⁸ As part of the Wisconsin SPNS initiative, ten "Linkage to Care Specialists" (LTCS) have been hired by community agencies to provide field-based, intensive, patient navigation support. LTCS will have approximately 10-15 clients from several different priority groups which will initially include:

- newly identified YBMSM;
- individuals with acute HIV infection;
- post-incarcerated individuals (scheduled for release from Department of Corrections facilities);
- priority individuals disengaged from HIV clinical care; and
- priority individuals who are "at-risk" for disengaging from HIV clinical care.

LTCS will provide an array of services to a highly-specific, hard-to-reach, group of clients and will not replace any existing services such as PS, CTR or medical case management. Examples of LTCS activities include:

- case finding and home-visits,
- assessment of barriers to care,
- active, facilitated referral and linkage to first three HIV clinical visits,
- coordination of support services that support linkage to and retention in care, and
- reengagement support and active facilitation

LTCS are currently located in five organizations in the southern and southeastern regions of the state and are assuming case assignments from specified clinical sites, the Department of Corrections, and AHI testing sites.

Data systems integration

One of the key goals of the SPNS initiative is to improve the use of data to support linkage and retention to HIV care. The AIDS/HIV Program will take a lead role in implementing a networked CAREWare system over the next few years for Ryan White providers. This networked data system will 1) improve care coordination by allowing data sharing across agencies for common clients and by improving client referrals and transfer of client information; 2) reduce the agency reporting burden; 3) encourage grantees to monitor basic quality of care measures; and 4) allow a system-wide assessment of the efficacy of the SPNS intervention, service utilization, and client demographics. Another data-related strategy is to improve the use of existing data to identify those individuals who are lost to care or at risk of falling out of care. At the state level, HIV surveillance, laboratory and AIDS Drug Assistance Program data will be used to identify individuals who were never linked to care or who have fallen out of care. This data will serve as the basis for follow-up activities. In addition, the AIDS/HIV Program will assist clinical sites in analyzing clinical visit data in the same way.

⁸ Gilman B, Hidalgo J, Thomas C, Au M, Hargreaves M. Linkages to care for newly diagnosed individuals who test HIV positive in non-primary care settings. AIDS Patient Care and STDs 2012; 26: 132–140.

Collaborative learning model and the model for improvement

SPNS demonstration sites are engaging community stakeholders through the Collaborative Learning Model (CLM).⁹ This model requires intensive, ongoing, stakeholder engagement to promote systems-level changes that improve outcomes. A steering committee, composed of AIDS/HIV Program staff and community partners from prevention, PS, and care and treatment organizations will move the Wisconsin SPNS initiative forward and generate community-wide support. The steering committee coordinated a successful "Learning Session" for more than 90 providers from 20 agencies across the state on April 26-27, 2012. This meeting identified systems-level gaps in the Wisconsin HIV service continuum. Four implementation groups were established at the Learning Session and are planning to develop pilot interventions to address service gaps. The implementation groups include *Acute HIV Testing*; *Partner Services and Initial Linkages*; *Retention in Care*; *and Data Systems & Evaluation*. The next Learning Session, scheduled for November 8-9, 2012, will enable agencies that are part of the SPNS initiative to showcase their work and expand collaborative networks.

Summary

Wisconsin's linkage to care initiative, supported by the federal SPNS grant, is a unique opportunity to improve the quality of life for persons living with HIV in Wisconsin and to decrease the incidence of HIV infections. Collaborative efforts among service providers are expected to ensure access to and engagement in quality prevention, care, and support services. This initiative holds promise for establishing positive health outcomes that result from more persons:

- becoming aware of their HIV infection,
- initiating HIV-related care,
- staying engaged in care and effective treatment therapies, and
- maintaining behaviors that prevent the further transmitting of HIV.

For further information about the SPNS Linkage to Care initiative and how agencies can participate in the Collaborative Learning Model, contact Mari Ruetten, Ryan White Coordinator, at (608) 261-6397, or email <u>mari.ruetten@wisconsin.gov</u>.



⁹ Institute for Healthcare Improvement. The breakthrough series: IHI's collaborative model for achieving breakthrough improvement. IHI Innovation series white paper. Boston: IHI; 2003. Available from <u>http://www.ihi.org/knowledge/Pages/IHIWhitePapers/TheBreakthroughSeriesIHIsCollaborativeModelforAchieving</u> <u>BreakthroughImprovement.aspx</u>