

Using Consumer LINC Models to Address New Legislative Requirements around HIV+/Unaware Individuals

New Legislative Requirements

The Ryan White HIV/AIDS Treatment Extension Act passed in October 2009 provides an expanded focus and new requirements on getting people with HIV/AIDS into care as soon as possible after they become infected.

The 2000 legislation required a new focus on reducing unmet need – finding people who know they are HIV+ and helping them enter and remain in HIV-related medical care. The 2006 legislation maintained the requirement and added a focus on people living with HIV/non-AIDS as well as people living with AIDS. The 2006 legislation required Part A Planning Councils (or the grantee where there is no planning council) and Part B programs to:

- Determine the size and demographics of the population of individuals with HIV/AIDS
- Assess PLWH service needs and gaps “with particular attention to individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services” and “disparities in access and services among affected subpopulations and historically underserved communities”
- Develop a comprehensive plan for the organization and delivery of health and support services that “*includes a strategy for identifying individuals who know their HIV status and are not receiving such services...*”

The 2009 legislation simply adds *individuals who are unaware of their status* to all three requirements, including *a strategy for identifying individuals and enabling them to use the health and support services described.*

For Part A programs, there are “teeth” in the legislation because about one-third of Part A funds are awarded through a competitive process (the other two-thirds are awarded through a formula based on the number of people living with HIV and AIDS in the service area). Since 2006, one-third of the competitive score awarded for Part A supplemental funding applications has been based on “demonstrated need,” which includes unmet need. As of 2009, another one-third is based on the program's “demonstrated success” in getting undiagnosed individuals tested and into care. Planning Councils have a specific role in this effort. As the House of Representatives Committee Report indicates:

“Section 6 encourages early identification of individuals infected with HIV. It requires the planning councils for Part A grant recipients to develop a strategy, in coordination with other appropriate community strategies or activities, to identify and diagnose individuals with HIV/AIDS who are unaware of their status and link them with the appropriate care and treatment.”

Part B grantees [and Part A Transitional Grant Areas that do not have Planning Councils] have the same requirement “as part of their planning process for Ryan White funding.”

The HIV/AIDS Bureau is exploring how best to implement the requirements for getting HIV+/unaware people tested and then into care. A consultation with the Centers for Disease Control and Prevention (CDC) and a small number of grantees was scheduled for February 8 but postponed to April 12-13 because of the Big Snow in Washington, DC. A better sense of data availability and methods for estimating the number and characteristics of the HIV+/unaware population are expected following that consultation, which Project LINC will be attending.

Importance of the Use of Peers

It is already clear (as stated in the letter to grantees sent by the HIV/AIDS Bureau in late February), that the use of consumers is viewed by HAB as an important strategy for addressing both unmet need and the new legislative requirements. The new legislation makes the engagement of consumers in linking other PLWH to care especially important for several reasons:

- **Need for new and effective strategies to get people tested and into care:** The focus of the legislation on getting people into care as soon as possible after they become HIV+ will require Ryan White grantees to find effective and affordable strategies for finding such individuals. The documented experiences in other diseases indicates that consumer/peer-based strategies can be extremely effective – much more so than many current strategies.
- **Need for affordable strategies:** As more people are tested and brought into care, care and treatment resources will be stretched increasingly thin since treatment funds are increasing only modestly – and mostly for medications (AIDS Drug Assistance Program). Consumers serving as community health workers offer a cost-effective source of staff expertise. PLWH committee or caucus members assisting as volunteers or with small stipends are even more cost-effective.
- **HIV/AIDS as a chronic illness:** As HIV/AIDS becomes viewed and treated as a chronic illness, there is a growing recognition of the need to increase PLWH disease self-management capacity so resources are focused on those new to care and those with co-occurring conditions or special needs. As demonstrated in diabetes management and care, peer models can improve medical outcomes and reduce the cost of care by helping people learn to navigate the system of care.

Using Consumer LINC Strategies to Address the New Requirements

All four of the Consumer LINC strategies can contribute to both addressing unmet need and helping HIV+/unaware people get tested and enter care:

- **Strategy #1 – Understanding and Refining the System of Care:** The analysis can be broadened to include the system of *testing and care*, and peers can play a key role in identifying barriers to getting tested and getting newly tested PLWH into care, and recommending improved linkages between prevention and care.
- **Strategy #2 – PLWH Caucus/Committee:** PLWH groups can work equally effectively with PLWH who know their status and with individuals who need to get tested. Peers can urge people in their networks not only to enter care if they have been tested, but also to get tested if they don't know their status. They can do outreach to communities at high risk as well as

already-diagnosed PLWH. They can educate people about the importance of early care in reducing transmission and improving long-term health.

- **Strategy #3 – Linking PLWH to Care:** Depending on what role the HIV/AIDS Bureau asks Part A and Part B programs to play in outreach to those who are unaware of their status and in testing, peers can play a key role in both street outreach and early intervention services (EIS). They can help ensure a strong link between testing and care. Already within the strategy is the role of helping newly diagnosed PLWH deal with their diagnosis, understand the benefits of entering care immediately, and enter care.
- **Strategy #4 – Integrated Clinical Care Team:** In this strategy, peers play a key role in ensuring that newly diagnosed PLWH can navigate the system of care and become fully connected to care. The new legislative requirements call not only for increased testing but also for getting newly tested PLWH to enter care.

Estimating the Size and Characteristics of the HIV+/Unaware Population

In planning which strategies to use and developing specific plans for implementation, it is important first to understand the populations you are trying to reach. To find people with unmet need and help them enter care, you need to target efforts based on their characteristics, place of residence, and barriers to care. It is also helpful to categorize PLWH with unmet need so you can focus on the most promising points of entry into care. The four suggested categories are the newly diagnosed, those who are receiving some services (often support services like food and nutrition) but not HIV-related medical care, those who are known to the care system but dropped out of care, and those who have never been in care.

To successfully find HIV+/unaware individuals and help them get tested and into care will require similar assessment of their characteristics, place of residence, and barriers to testing and care. This will be more challenging, but approaches will be developed. Mosaica suggests the following approach to get a sense of who is likely to be HIV+/unaware, so you can target your efforts:

- Assume that HIV+/unaware individuals are likely to be *similar in characteristics to certain groups of PLWH who know their status*, such as the following. Review the demographic profiles including place of residence of these groups, using surveillance data, supplemented by needs assessment studies/data:
 - The met need population (people in care)
 - The unmet need population (people out of care)
 - Recently tested/diagnosed individuals (diagnosed in past 12 months)
 - Recently tested/diagnosed people with HIV/non-AIDS (diagnosed in past 12 months)
 - Late-diagnosed individuals – people diagnosed with AIDS at the time of testing or within 12 months afterwards (diagnosed in past 12 months)
- Review national data on HIV+ rates among specific groups (e.g., incarcerated, injection drug users) and look at the size of these populations in your service area.
- Based on these analyses, make an adjusted estimate of the number of HIV+/unaware people in your service area (the basic estimate is that about one-fourth of people with HIV/AIDS are unaware of their status).
- As people are tested and brought into care, continue to monitor their characteristics in order to refine your efforts.