2015–2020 National HIV/AIDS Strategy Goals for HIV Linkage and Retention in Care: Recommendations From Program Implementers

The updated 2015–2020 National HIV/AIDS Strategy guides ending the US HIV epidemic.[1–3] Its goals are to (1) reduce HIV infections, (2) increase access to care and improve health outcomes for people living with HIV, (3) reduce HIV-related health disparities and health inequities, and (4) achieve a more coordinated national response to the HIV epidemic.[2]

Recent scientific and policy advances enhanced the tools to address this epidemic. These include treatment as prevention, pre-exposure prophylaxis, and the Affordable Care Act.[2] New diagnoses decreased among women, persons who inject drugs, and heterosexuals but are increasing among men who have sex with men.[4] Furthermore, disparities in the HIV continuum of care persist across demographic groups.[5] In particular, African Americans experience delayed linkage to care and higher disease mortality compared with people living with HIV of other races.[6,7] In the overall US continuum of care, only 40% of individuals living with HIV were successfully engaged in care, 37% had been prescribed antiretroviral therapy, and 30% had suppressed viral loads as of 2011.[8]

The second goal of the National HIV/AIDS Strategy, increasing access to care, addresses these gaps. Its five progress indicators are as follows (quoted as they appear in the National HIV/AIDS Strategy):

(1) increase the percentage of newly diagnosed persons linked to HIV medical care within one month of their HIV diagnosis to at least 85%,
(2) increase the percentage of persons with diagnosed HIV infection who are retained in HIV medical care to at least 90%,
(3) increase the percentage of persons with diagnosed HIV infection who are virally suppressed to at least 80%,
(4) reduce the percentage of persons in HIV medical care who are homeless to no more than 5%, and
(5) reduce the death rate among persons with diagnosed HIV infection by at least 33%.[2]

The White House released a federal action plan with steps for implementing the strategy in December 2015.[9]

Below are recommendations derived from the five networks of agencies who were part of an AIDS United initiative called Positive Charge.[10] These agencies worked across Louisiana; Chicago, Illinois; New York City, New York; North Carolina; and the San Francisco Bay Area, California, from 2010 to 2013. Positive Charge sought to address the needs of people living with HIV who had never engaged in or had dropped out of care. Each site designed a program tailored to their population and collaborated with local partners. Partners included medical providers, AIDS service organizations, local public health departments, and social service organizations.

Each site participated in a rigorous, cross-site evaluation including qualitative case studies. These recommendations arise from conventional content analysis of transcripts from 40 interviews from 27 organizations in five geographies from June 2011 to October 2012.[11] The process and results of the cross-site evaluation have been described in detail elsewhere.[11–14] Following Positive Charge, 88% of participants from three sites were engaged in care, 69% were retained in care, and 46% were virally suppressed. The remaining two sites lacked access to medical visits and laboratory data.[15] As noted previously, nationally there was 40% engagement in care and 30% viral suppression. Thus, lessons learned from these sites may inform practices to improve lives for people living with HIV and close the gaps in the US HIV continuum of care. Within each recommendation, we suggest their most proximal National HIV/AIDS Strategy indicators.

The recommendations are as follows:

1. *Recognize and plan for a complex constellation of, and disparities in, client needs*: Staff commented on the unexpected intensity of client needs and felt somewhat unprepared to address them given the multidimensional nature of these needs. Staff reported that many clients had co-occurring unmet needs for housing, substance abuse treatment, employment, and mental health services that kept them from care (often these needs were reflective of the

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health disparities in the HIV epidemic in the United States).[16–18] Specifically, at enrollment, 37% of Positive Charge participants reported needing housing, and 41% had an unmet need for food or other subsistence. When asked about their single most important need, 17% reported housing (C. Maulsby, personal communication, 2015). Future programs might allocate time and resources to manage clients' unmet needs keeping them from care. Estimates of the time to link a particular client into care should reflect the time required for the program to start the process of addressing participants' outstanding needs. This recommendation most closely relates to National HIV/AIDS Strategy indicators 4, 5 and 7.

2. *Nurture and cultivate interorganizational networks*: While establishing a network of organizations took consistent effort and close management, respondents at all project sites reported strong, concrete benefits such as referrals or provision of social services needed by clients. Participating organizations found that engaging partners early in the program strengthened their networks. Previous studies find that collaboration begins through information sharing, followed by referrals, and finally, sharing resources.[19] Formal learning communities or ongoing meetings may also prove helpful. This recommendation addresses indicators 5 and 7 as retention and stable housing often rely on strong interorganizational partnerships.
3. *Proactively establish HIPAA-compliant procedures to share information about clients or potential clients*: Establishing relationships with organizations with lists of out-of-care clients before implementation eased starting the linkage process. Sites may establish HIPAA-compliant memoranda of understanding (MoUs) early on, which could enable partners to share information about eligible individuals (e.g., between an AIDS service organization and clinical partners). MoUs have an advantage as they allow organizations to gain information on an individual before they are contacted. Client release forms also allow sharing client information between organizations while respecting confidentiality. This recommendation relates to indicators 4 and 5.
4. *Build strong relationships with medical providers*: Programs lacking preexisting relationships with medical providers could cultivate such relationships by using a variety of ways to connect with this group. Partnerships should be established as early as possible. Co-locating case managers and other linkage-to-care workers in clinical settings may provide an opportunity to build these relationships. This recommendation relates to reaching indicators 4, 5, and 6.
5. *Involve peers, or other health navigators, to support clients in engagement in care*: All of the programs employing peers as linkage-to-care workers found peers to be vital for program success. This recommendation leads to meeting indicators 4, 5, 6, and 7. Our experience suggests that creating a supportive, enabling work environment for peers is critical. Recommendations include providing peers with resources (e.g., office space) and clarifying peer roles versus case manager roles initially.
6. *Organizational development and capacity building*: The experiences of these groups suggest that ongoing organizational issues, such as turnover among staff and partner organizations, pose a particular challenge to linkage-to-care programs. Recommendations for addressing staff turnover include establishing contingency plans in case of absences or unanticipated staff changes. Increasing organizational capacity includes offering training or mentorship for work in new areas (e.g., for staff new to computer use in a professional setting). This recommendation is a necessary step for reaching each National HIV/AIDS Strategy goal 2 indicator.

We hope these findings inform implementers and policymakers by highlighting strategies to overcome challenges in designing and running successful HIV linkage and retention in care programs. AJPH

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REFERENCES

1. Office of National AIDS Policy. National HIV/AIDS Strategy for the United States. 2010. Available at: http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf. Accessed May 12, 2014.

2. Office of National AIDS Policy. National HIV/AIDS Strategy for the United States. 2015. Available at: https://aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf. Accessed August 1, 2015.

3. Holtgrave DR, Greenwald R. A SWOT Analysis of the Updated National HIV/AIDS Strategy for the US, 2015–2020. *AIDS Behav*. 2015;Epub ahead of print.

4. Centers for Disease Control and Prevention. HIV Surveillance Report: Diagnoses of HIV Infection in the United States and Dependent Areas. 2013. Available at: http://www.cdc.gov/hiv/library/reports/surveillance/index.html. Accessed August 3, 2015.

5. Centers for Disease Control and Prevention. HIV in the United States: The Stages of Care. 2014. Available at: http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Stages-of-Care-Factsheet-508.pdf. Accessed September 20, 2015.

6. Lesko CR, Cole SR, Miller WC, et al. Ten-year survival by race/ethnicity and sex among treated, HIV-infected adults in the United States. *Clin Infect Dis*. 2015;60(11):1700–1707.

7. Ulett KB, Willig JH, Lin H-Y, et al. The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care STDS*. 2009;23(1):41–49.

8. Centers for Disease Control and Prevention. Understanding the HIV Care Continuum. Available at: http://www.cdc.gov/hiv/statistics/systems/mmp/resources.html. Accessed Aug. 1, 2015.

9. AIDS.gov. Federal Implementation. Available at: https://www.aids.gov/federal-resources/national-hiv-aids-strategy/strategy-implementation/federal-implementation. Accessed August 2, 2015.

10. Kim JJ, Maulsby C, Kinsky S, et al. The development and implementation of the national evaluation strategy of Access to Care, a multi-site linkage to care initiative in the United States. *AIDS Educ Preven*; 2014;26(5):429–444.

11. Jain KM, Holtgrave DR, Maulsby C, et al. *Improving Access to HIV Care: Lessons From Five US Sites*. Baltimore, MD: Johns Hopkins University Press; 2016.

12. Kim JJ, Maulsby C, Zulliger R, et al. Cost and threshold analysis of Positive Charge, a multi-site linkage to HIV care program in the United States. *AIDS Behav*. 2015;19(10):1735–1741.

13. Kinsky S, Maulsby CH, Jain KM, et al. Barriers and facilitators to implementing access to HIV care interventions: a qualitative analysis of the Positive Charge initiative. *AIDS Educ Prev*. 2015;27(5):405–417.

14. Maulsby C, Kinsky S, Jain KM, et al. Unpacking linkage and reengagement in care: a day in the life of a Positive Charge care coordinator. *AIDS Educ Prev*.2015;27(5):405–417.

15. Maulsby C, The Positive Charge Intervention Team, Charles V, et al. Positive Charge: filling the gaps in the US HIV continuum of care. *AIDS Behav*. 2015;19(11):2097-2107.

16. Wolitski RJ, Kidder DP, Pals SL, et al. Randomized trial of the effects of housing assistance on the health and risk behaviors of homeless and unstably housed people living with HIV. *AIDS Behav*. 2009;14(3):493–503.

17. Meyer JP, Althoff AL, Altice FL. Optimizing care for HIV-infected people who use drugs: evidence-based approaches to overcoming healthcare disparities. *Clin Infect Dis*. 2013;57(9):1309–1317.

18. Philbin MM, Tanner AE, DuVal A, Ellen J, Kapogiannis B, Fortenberry JD. Linking HIV-positive adolescents to care in 15 different clinics across the United States: creating solutions to address structural barriers for linkage to care. *AIDS Care*. 2014;26(1):12–19.

19. Provan KG, Nakama L, Veazie MA, Teufel-Shone NI, Huddleston C. Building community capacity around chronic disease services through a collaborative interorganizational network. *Health Educ Behav*. 2003;30(6):646–662.