

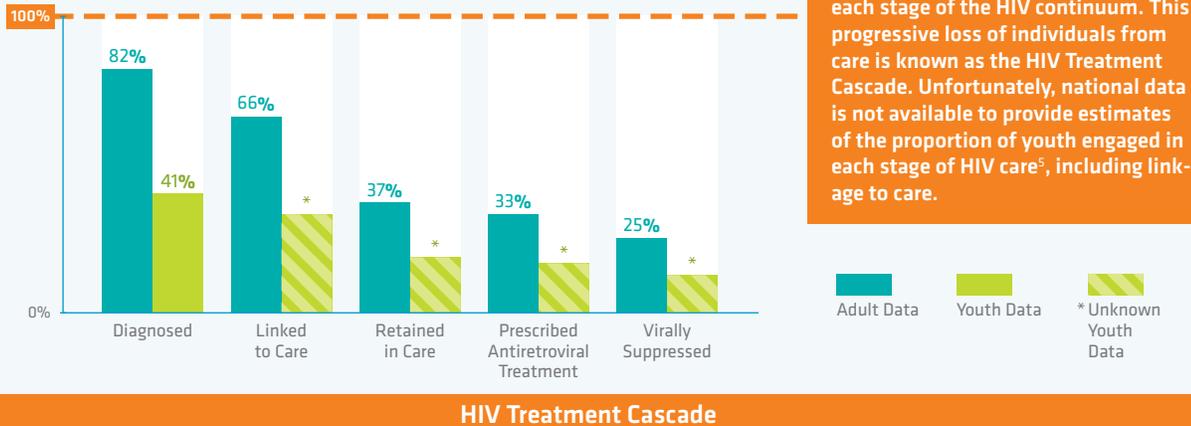
Linkage to Care for Youth: Lessons Learned from Project SMILE

(The Strategic Multi-site Initiative for Linkage and Engagement in HIV-related Care)

This Research to Practice Brief, *Linkage to Care for Youth: Lessons Learned from Project SMILE*, is part of a series developed by the Center



for Strengthening Youth Prevention Paradigms (SYPP Center) at Children's Hospital Los Angeles, to ensure that emerging research on HIV prevention is available to service providers. These briefs focus on the implications of research findings for service delivery rather than on the findings themselves. We hope this brief will inform your planning and facilitate the adoption of best practices for HIV/AIDS prevention and care for youth and young adults in your community.



Fewer people are engaged in care at each stage of the HIV continuum. This progressive loss of individuals from care is known as the HIV Treatment Cascade. Unfortunately, national data is not available to provide estimates of the proportion of youth engaged in each stage of HIV care⁵, including linkage to care.

What is Project SMILE?

The Strategic Multi-site Initiative for Linkage and Engagement in HIV-related Care (Project SMILE) is a five-year project (2010–2015) funded through a partnership between the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the Centers for Disease Control and Prevention (CDC), and the Adolescent Trials Network for HIV/AIDS Interventions (ATN). The purpose of Project SMILE is to develop and test protocols to ensure that all youth ages 12–24 diagnosed with HIV are linked to HIV medical care and engaged and retained in care in order to improve their outcomes and reduce the risk of transmission. Project SMILE's approach is based on the multiple steps in the HIV continuum of care needed to achieve undetectable viral loads—testing, diagnosis, linkage to care, engagement in care, retention, and medication adherence.

Phase I of Project SMILE (2010–2012) focused on strategies to improve linkage to care (LTC) by improving the relationship between testing and treatment sites. (Specific findings from Phase I are posted on the ATN website as publications are released: www.atnonline.org.) Phase II of Project SMILE (2012–2015) continues strategies from Phase I with an additional focus on strategies to overcome other structural barriers in practices, programs and policies that interfere with successful linkage and engagement in HIV care services of newly identified HIV-positive youth.

What is Structural Change and Why is it Important to HIV Prevention?

Structural change is an approach to HIV prevention and care that targets practices, programs, or policies, instead of individuals, in order to improve services and resources and impact the social and environmental factors that influence a person's risk for HIV and their health and treatment outcomes if they are positive.¹ Structural interventions can achieve sustainable improvements in HIV/AIDS prevention and service delivery systems. Structural change interventions require the involvement of key agencies and institutions and emerge from a thorough assessment of a community's needs, resources, gaps, and readiness.

Currently, as many as 60% of youth living with HIV are not in routine HIV care² which significantly increases their risk of morbidity and mortality and the risk of HIV transmission. Structural change strategies have emerged as a critical component of HIV/AIDS prevention to help address this issue. There is evidence that increasingly smaller numbers of people make it through each stage of the HIV continuum of care to achieve undetectable viral loads, and this progressive loss of HIV-positive individuals from the continuum of HIV care is referred to as the "HIV treatment cascade"^{3,4} (see above). Far too many individuals fall out of care at each stage of the continuum, and the cascade model helps us identify which HIV-positive individuals are not engaged in care and at what stage we're losing them. Armed with this

information, we can determine specific system improvements and service enhancements (i.e., structural change) to improve linkage, engagement, and retention in care, thus improving treatment outcomes and reducing the risk of HIV transmission for young people in our communities.

What Have We Learned from Project SMILE to Strengthen HIV/AIDS Prevention?

Findings from Phase I of Project SMILE suggest that we can reduce the risk of HIV transmission and improve treatment outcomes for HIV-positive youth if we specifically focus on improving our processes and services so that all youth diagnosed with HIV are linked to HIV care.

The Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) was created in 2001 to develop and implement youth-specific research protocols for HIV-positive and at-risk youth and young adults ages 12–24 in order to improve primary prevention for at-risk youth and treatment outcomes for HIV-positive youth, and to reduce the risk of HIV transmission. The ATN is sponsored by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute on Drug Abuse, and the National Institute of Mental Health. Additional information may be found at: www.atnonline.org.

Communities can improve linkage to care (LTC) for HIV-positive youth by implementing structural solutions identified through Project SMILE:

- ➔ **Engage local health departments and community planning groups**
 - » Work with your health department and community planning group to get them to focus on youth and commit resources to link HIV positive youth to the care they need.
- ➔ **Organize key resources and develop clear protocols and procedures for LTC**
 - » Organize your health department, HIV treatment sites, HIV agencies and networks, and youth-specific agencies and networks to work together to improve LTC.
 - » Identify gaps and barriers in your community that interfere with LTC.
 - » Work with your partner agencies to develop clear time frames for each step of the linkage process (e.g., time from referral to initial medical appointment, time from first appointment to second appointment, number of appointments youth should have).
 - » Specify the roles and responsibilities of each key agency in the linkage process.
 - » Identify what your agency is going to do to facilitate LTC and support the linkage process.
 - » Create formal agreements and protocols for LTC between your local health department, other HIV testing sites, HIV treatment sites, and youth-serving and HIV-related agencies.
 - » Develop data-sharing agreements between your health department, treatment sites, and other youth- and HIV-related agencies to facilitate access to public health information for designated staff to help identify which youth need additional intervention and support to achieve LTC.
- ➔ **Dedicate staff to linkage/engagement efforts**
 - » Dedicate outreach staff that can: 1) accept referrals of youth who test positive from health departments and other testing sites; 2) link youth to treatment sites; and 3) follow up with youth and with treatment sites to ensure youth are linked to care.
 - » Train outreach staff to ensure their competence to work with youth and their capacity to manage crises.
 - » Provide supervision and support so outreach workers can follow protocols, implement procedures, identify barriers, and respond to youth's needs.
- ➔ **Ensure services are youth-friendly**
 - » Adopt youth-friendly, culturally-competent practices in clinics and other service sites.
 - » Ensure that your facilities are safe, appealing and easily accessible to youth and staffed with people who are interested in and skilled at providing care to youth.
- ➔ **Evaluate processes and outcomes and modify strategies, protocols, and procedures as needed**
 - » Periodically assess whether stakeholders are involved, and develop strategies to engage new partners and sustain participation as needed.
 - » Develop and monitor formal processes and procedures to evaluate the adequacy of your services and supports.
 - » Disseminate data you collect to your partner agencies for use in improving your linkage process.
 - » Monitor outcomes to determine if HIV-positive youth in your community are linked to care.

Examples of Structural Changes Related to Linkage to Care

- » A community clinic requires all staff, volunteers, and contractors to attend trainings on youth-friendly, culturally competent practices.
- » A community organization that provides HIV testing and a clinic that provides HIV treatment create a formal linkage to care agreement.
- » A health department implements a new pay-for-performance reimbursement policy that rewards successful linkage to care.

What Can You Do With this Information to Promote Linkage to Care?

The results from Project SMILE demonstrate that structural interventions can improve linkage to care for HIV-positive youth. Each community may be at a different stage of readiness. Start by making a commitment within your own agency to improve linkage to care and work within your own networks to engage other key stakeholders in the process. Ultimately, to be successful, local health departments and community planning groups must be engaged and committed.

Regardless of where you are in the process of improving linkage to care, you can advance HIV prevention efforts and reduce the risk of HIV transmission by adopting best practices identified through Project SMILE.

References

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The Center for Strengthening Youth Prevention Paradigms (SYPP Center) is a capacity building assistance (CBA) project housed in the Risk Reduction Program at the Division of Adolescent Medicine at Children's Hospital Los Angeles. Founded in 2009 and funded through a grant by the Centers for Disease Control and Prevention, SYPP Center offers a framework for communities to use in their HIV/AIDS prevention efforts. The Center's CBA services help communities build strong coalitions capable of responding to local conditions and achieving sustainable structural-level changes to prevent HIV/AIDS and reduce transmission among young gay men and transgender youth of color. Additional information and resources may be found at: www.chla.org/sypp.

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