

Implementation of an Integrated Approach to the National HIV/AIDS Strategy for Improving Human Immunodeficiency Virus Care for Youths

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IMPORTANCE Youths aged 13 to 24 years old living with human immunodeficiency virus (HIV) are less likely than adults to receive the health and prevention benefits of HIV treatments, with only a small proportion having achieved sustained viral suppression. These age-related disparities in HIV continuum of care are owing in part to the unique developmental issues of adolescents and young adults as well as the complexity and fragmentation of HIV care and related services. This article summarizes a national, multiagency, and multilevel approach to HIV care for newly diagnosed youths designed to bridge some of these fragmentations by addressing National HIV/AIDS Strategy goals for people living with HIV.

DESIGN, SETTING, AND PARTICIPANTS Three federal agencies developed memoranda of understanding to sequentially implement 3 protocols addressing key National HIV/AIDS Strategy goals. The goals were addressed in the Adolescent Trials Network, with protocols implemented in 12 to 15 sites across the United States. Outcome data were collected from recently diagnosed youth referred to the program.

MAIN OUTCOMES AND MEASURES Cross-agency collaboration, youth-friendly linkage to care services, community mobilization to address structural barriers to care, cooperation among services, proportion of all men who have sex with men who tested, and rates of linkage to prevention services.

RESULTS The program addressed National HIV/AIDS Strategy goals 2 through 4 including steps within each goal. A total of 3986 HIV-positive youths were referred for care, with more than 75% linked to care within 6 weeks of referral, with almost 90% of those youths engaged in subsequent HIV care. Community mobilization efforts implemented and completed structural change objectives to address local barriers to care. Age and racial/ethnic group disparities were addressed through targeted training for culturally competent, youth-friendly care, and intensive motivational interviewing training.

CONCLUSIONS AND RELEVANCE A national program to address the National HIV/AIDS Strategy specifically for youths can improve coordination of federal resources as well as implement best-practice models that are adapted to decrease service fragmentation and systemic barriers at local jurisdictions.

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The human immunodeficiency virus (HIV) continuum of care (care continuum) describes the proportion of people living with HIV who are aware of their infection, have entered HIV-related care, and achieved viral suppression.¹ In the United States, an estimated 87% of the more than 1 million people living with HIV are aware of their diagnosis, 84% of whom are subsequently linked to care within 3 months, with 56% of those linked to care subsequently retained in care and 77% of those engaged in care ultimately achieving viral suppression.² However, among persons aged 13 to 24 years, care continuum outcomes are even worse. Only 49% of the estimated 60 900 youths living with HIV are aware of their diagnosis, 80% of whom are linked to care within 3 months, with 53% retained in care and 61% of those in care virally suppressed.²

Causes of the marked disparities for youths along the entire care continuum relate in part to the complexity of the HIV care system that must be accessed and navigated. This complexity is owing to the numerous requirements, required actions, and milestones needed to successfully attain a given outcome. For example, the apparently straightforward task of linkage to care for newly diagnosed youths simultaneously involves crisis management, education about HIV and associated comorbidities, disclosure to others, delivery of any needed treatments, and ensuring access to appropriate entitlements to pay for care.³ Age itself is an important contribution to care continuum disparities for youths because newly diagnosed young people have limited experience with health care systems and face legal or procedural barriers in obtaining care.⁴ Significant missed opportunities, represented as losses along the care continuum, occur when infected youths are untested (resulting in lack of awareness of HIV status),⁵ when there are delays in connection with HIV-focused health care (resulting in failure of timely linkage to care),⁶ when there is no therapeutic relationship with health care professionals and staff (resulting in lack of engagement in care),⁷ and when youths fail to maintain long-term relationships with health care professionals and clinics (resulting in unsuccessful retention in care and ultimately poor rates of initiation of antiretroviral medications, adherence, and viral suppression).⁸ Sexual minority youths living with HIV often do so without significant parental support because of stigma and rejection owing to sexual identity and behavior. Taken together, the disparities faced by youths infected with HIV require a coordinated effort across multiple sectors and systems to create the sustained, systematic attention to key issues of HIV prevention and treatment unique to youths that will be needed to successfully affect the domestic epidemic among our young people.⁹

One approach to ameliorating care continuum disparities for newly diagnosed youths is a focus on reducing fragmentation of the complex systems of health care and support services associated with HIV care.^{10,11} Although reduction of care fragmentation is an explicit objective of the National HIV/AIDS Strategy (NHAS): Updated to 2020,¹² federal, state, and local policies and practices contribute to fragmentation in HIV care including the separation of HIV testing and prevention services from HIV treatment and care systems.¹³ For example, testing and prevention activities are organized at a national level by the Centers for Disease Control and Prevention (CDC) and delivered by health departments at state and county levels.¹⁴ However, treatment services (along with some targeted testing) are funded through national programs, such as the Health Resources and Services Administration's Ryan White HIV/AIDS program, with an ar-

ray of public, private for-profit organizations, and nonprofit organizations delivering local services.¹⁴ Services required for optimal health outcomes, eg, mental health, addiction, or reproductive health services, may be additionally disconnected at both payer and provider levels.¹⁵ With the larger objective of improving HIV care for youth, we describe here a nationally relevant, multiagency, and multilevel approach to reducing fragmentation of HIV care for youth. Outcome evaluations of this approach are briefly summarized, and recommendations for next steps are discussed.

Methods

The program described here was based in the implementation research network of the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN). The ATN is a national youth-focused HIV research network supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute of Mental Health, and the National Institute for Drug Abuse.^{6,16} The implementation research program contained 7 elements: (1) create a federal interagency collaboration to guide overall design and implementation; (2) deploy full-time linkage to care coordinators; (3) develop formal referral to care networks; (4) develop local linkage to care partnerships; (5) obtain public health authority from local health departments; (6) deploy structural changes to improve linkage to care; and (7) increase clinical capacity for youth-friendly HIV care. Each element was incorporated into 1 or more of 3 sequentially implemented research protocols. Each element also corresponded to at least 1 NHAS goal (Table 1).¹²

The federal agency collaboration included representatives of Eunice Kennedy Shriver National Institute of Child Health and Human Development, the CDC, and Health Resources and Services Administration. The agencies signed on to memoranda of understanding, meeting monthly to review protocol design, provide technical assistance, monitor implementation, and summarize outcomes. Each protocol was independently approved by each participating site.

Three protocols were sequentially implemented from 2009 through 2013, with final data collection in 2016. The first protocol was named The Strategic Multisite Initiative for the Identification, Linkage to and Engagement in Care of Youth With Undiagnosed HIV-infection (SMILE 1), started in 2009 in 15 ATN sites in the United States and Puerto Rico. The programmatic objectives of SMILE 1 were to improve the identification of youths living with HIV and their uptake of and long-term retention in linkage and care services. Additionally, an integral implementation science objective of this collaborative was a process evaluation to characterize the care continuum for newly diagnosed youths at urban epicenters across the nation and to develop the evidence basis to inform best-practice guidelines and ongoing refinements of this program.¹⁷ Key elements of each protocol are depicted in Figure 1.

The Strategic Multisite Initiative for the Identification, Linkage to and Engagement in Care of Youth With Undiagnosed HIV-infection had 3 elements: (1) a full-time equivalent linkage to care coordinator; (2) active creation of formal referral networks of testing sites and HIV service clinicians; and (3) formal memoranda of understanding between each SMILE program site and its local health department. The linkage to care coordinator provided a range of services that were flexibly adapted to fit site-specific needs. Some sites

Table 1. Overall Program Tasks, Implemented Protocol, and Corresponding National HIV/AIDS Strategy (NHAS) Goal for SMILE/PEACOC, 2009-2016

Task	Protocol			NHAS Goal ^a	Key Outcomes
	SMILE 1	SMILE 2	PEACOC		
Create federal interagency MOU	Deployed in protocol	Deployed in protocol	Deployed in protocol	4, Step 4A	Interagency MOU completed by NICHD, CDC, HRSA
Deploy full-time linkage to care coordinator	Deployed in protocol	Deployed in protocol	Deployed in protocol	2, Step 2A	Improved linkage to care success ²¹
Develop formal referral to care networks	Deployed in protocol	Deployed in protocol	Deployed in protocol	2, Step 2A	Addressed multiple issues including navigating health insurance, transportation, and information sharing between testing agencies, local health departments and clinics; lack of youth friendliness within clinic space and staff, and duplication of linkage services ²²
Develop local linkage to care partnerships	Deployed in protocol	Deployed in protocol	Deployed in protocol	2, Step 2C	Reduced service duplication and increased capacity to provide services across local and regional catchment areas
Obtain public health authority from local health department	Deployed in protocol	Deployed in protocol	Deployed in protocol	2, Step 2A	Public health authority obtained by 6 sites although not all received real-time access to testing data ²³
Reduce health disparities in communities of high risk	Deployed in protocol	Deployed in protocol	Deployed in protocol	3, Step 3A	Decreased care fragmentation and increased care coordination
Deploy structural changes to improve linkage to care	Deployed in protocol	Deployed in protocol	Deployed in protocol	3, Step 3B	240 structural change objectives for youth addressing HIV testing (48%), linkage (41%), engagement and retention (11%) in HIV health care, and viral suppression (0.4%) ²⁴
Increase clinical capacity for youth-friendly HIV care	Deployed in protocol	Deployed in protocol	Deployed in protocol	2, Step 2C	Developed key skills for motivational interviewing and youth-specific cultural and clinical competence ⁶

Abbreviations: CDC, Centers for Disease Control and Prevention; HIV, human immunodeficiency virus; HRSA, Health Resources and Services Administration; MOU, memoranda of understanding; NHAS, National HIV/AIDS Strategy; NICHD, National Institute of Child Health and Human Development; PEACOC, Project for the Enhancement and Alignment of the Continuum of Care for HIV-Infected Youth; SMILE, The Strategic Multisite Initiative for the Identification, Linkage to and Engagement in Care of Youth With Undiagnosed HIV Infection.

^a Goal 2, Step 2A: establish seamless systems to link people to care immediately after diagnosis and support retention in care to achieve viral suppression that can maximize the benefits of early treatment and reduce transmission risk.

Goal 2, Step 2C: support comprehensive, coordinated, patient-centered care for

people living with HIV, including addressing HIV-related co-occurring conditions and challenges meeting basic needs, such as housing.

Goal 3, Step 3A: reduce HIV-related disparities in communities at high risk for HIV infection.

Goal 3, Step 3B: adopt structural approaches to reduce HIV infections and improve health outcomes in high-risk communities.

Goal 4, Step 4A: increase the coordination of HIV programs across the federal government and between federal agencies and state, territorial, tribal, and local governments.

established a protocol for face-to-face meetings of the linkage to care coordinator and a newly diagnosed adolescent or young adult at the point of diagnosis. The coordinator assessed readiness for care, provided information about HIV clinic visits, scheduled appointments, and maintained contact until the first clinic visit occurred.

Formal referral networks were emphasized in SMILE 1 because HIV testing sites are geographically dispersed in many communities while HIV medical care for youths is a limited-capacity specialty service.¹⁰ Lack of formal youth-specific linkage to care protocols among these diverse testing sites was a systemic barrier to care.^{3,18}

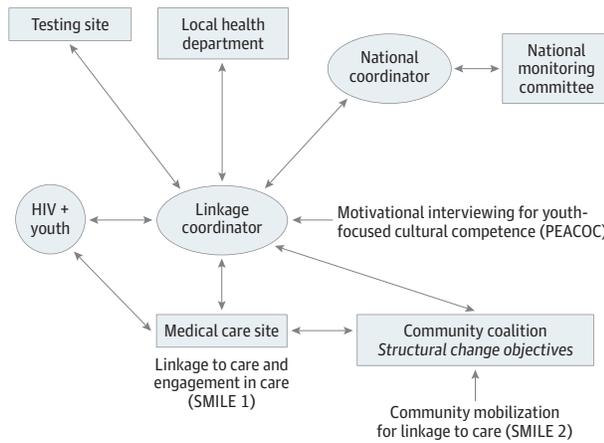
The formal memoranda of understanding between each site and its local health department included a request for public health authority. Public health authority would give SMILE project personnel access to protected health information as allowed by 45 Code of Federal Regulations § 164.512(b)(1)(i) (The Privacy Rule), which permits local health authorities to enter into formal agreements (eg, memoranda of understanding) to share personal health information with designated collaborators for the purposes of disease prevention and control.¹⁹ Public health authority provides a tool for HIV prevention, subject to jurisdictional interpretation of relevant regulations, and local ethical and legal challenges.^{18,20}

The Strategic Multisite Initiative for the Identification, Linkage to and Engagement in Care of Youth With Undiagnosed HIV-infection 2 was implemented in 2012, with 8 existing ATN sites

and 5 new ATN sites replacing those not refunded. The SMILE 2 protocol maintained the key elements of SMILE 1 but incorporated an additional community mobilization effort (called Connect to Protect) to bring key community stakeholder focus to address structural issues related to the entire care continuum for youth living with HIV.

The final protocol modification was designed to address racial/ethnic disparities (Project for the Enhancement and Alignment of the Continuum of Care for HIV-Infected Youth [PEACOC]; supported by the Secretary's Minority AIDS Initiative Fund). The SMILE 2 protocol sites were partnered with Health Resources and Services Administration Ryan White HIV/AIDS Program Part D sites colocated in the same cities or region. Formal partnerships between 4 Ryan White HIV/AIDS Program Part D sites and local Adolescent Medicine Trials Units addressed lack of cross-agency coordination of HIV services in many communities. Expectations for these formal partnerships included representation of the RWHAP Part D sites in the local Connect to Protect coalitions, as well as information sharing, shared best practices, matching of youths to most appropriate available services, and joint approaches to addressing local barriers to HIV-related care for youths. This elaboration of SMILE 2 in the context of an expanded national agency collaboration also addressed cultural competency by providing formal training in motivational interviewing for linkage to care coordinators.

Figure 1. Organization of the Strategic Multisite Intervention for Linkage and Engagement in Care (SMILE) and Project for the Enhancement and Alignment of the Continuum of Care for HIV-Infected Youth (PEACOC)



HIV indicates human immunodeficiency virus.

Results

Key outcomes of this large implementation science protocol are summarized in Table 1, although not all evaluation data have been analyzed and published. Outcomes are organized according to NHAS goals 2 through 4. The NHAS goal 1 addresses HIV prevention, which was not directly addressed by the protocols. Seven general findings were derived from program evaluations (Table 1).

Between 2009 and 2016, 3896 youths were referred for linkage to care, of whom, about 155 (9%) were younger than 18 years of age (Table 2). A substantially higher proportion of referrals came from SMILE 2/PEACOC (57%; 16 sites) compared with SMILE 1 (43%; 15 sites). The proportion of youths successfully linked to care (defined as a first medical visit within 42 days of testing) was higher in SMILE 2/PEACOC protocol (77%) than in SMILE 1 (70%), although the proportions engaged in care (defined as second medical visit within 3 months) were similar (86% and 89% for SMILE 2/PEACOC and SMILE 1, respectively). Viral load at referral was 15 474 copies/mL in SMILE 1 and 20 089 copies/mL in SMILE 2/PEACOC.

With respect to the NHAS goals, this program specifically addressed NHAS goal 4, step 4A: increase the coordination of HIV programs across the federal government and between federal agencies and state, territorial, tribal, and local governments. The successfully executed agreements among NICHD, CDC, and HRSA created the interagency support, guidance, and funding required for protocols to fully operationalize other NHAS goals. In addition, ongoing program participation by the federal agencies provided technical assistance and supported improved collaborations at each local level.

The program content focused primarily on NHAS goal 2. In this, we showed that specifically trained linkage to care coordinators were more effective at linkage to care than others and more effective in helping youths remain in care, especially in the context of public health authority (goal 2, step 2A); that community mobilization approaches could be used to implement structural changes address-

Table 2. Linkage and Engagement Outcomes

Linkage and Engagement Outcomes	No. (%)	
	SMILE 1	SMILE 2
Eligible for care (n = 3896)	1679 (43)	2217 (57)
Age <18 y	155 (9)	208 (9)
Men who have sex with men	1068 (64)	1341 (61)
African American	1112 (69)	1592 (72)
Linked to care	1172 (70)	1712 (77)
Engaged in care	1043 (89)	1467 (86)
Viral load at linkage to care, median, copies/mL	15 47436 ²⁵	20 089

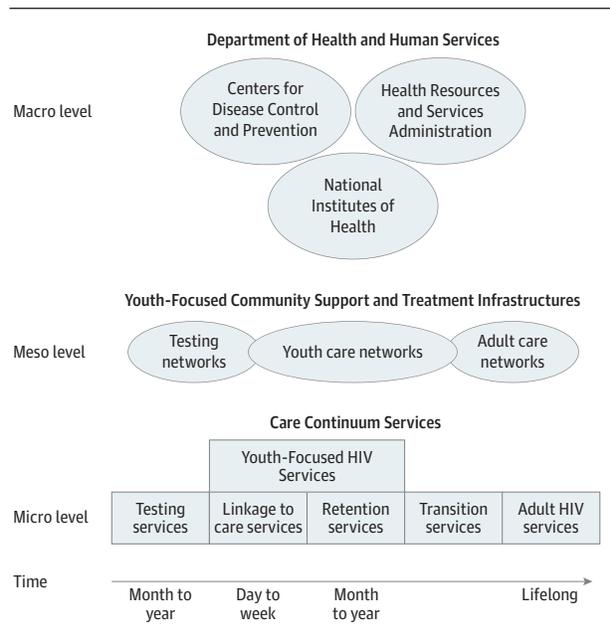
ing the entire continuum of care (goal 2, step 2B); that key health disparities in linkage to care could be systematically addressed; and access to youth-friendly HIV services supported access to HIV medical care in diverse settings across the United States (goal 2, step 2C).

Discussion

The National HIV/AIDS Strategy: Updated to 2020 sets as a key policy and action step to "increase the coordination of HIV programs across the federal government..."¹² In formalizing a 3-agency collaboration that operationalized and implemented interventions to address care fragmentation for youths living with HIV, we sought to improve health outcomes by addressing this goal. The multiagency collaboration permitted a sequence of implementation science protocols to directly address key elements of other NHAS goals (goal 2: increase access to care and improve health outcomes and goal 3: reduce HIV-related disparities and health inequities). We developed and implemented an integrated, multidimensional continuum of care model that guided the overall program design, administration, implementation, and evaluation of this project. This model may be useful for future efforts in addressing NHAS goals.

The integrated, multisystems continuum of care model is based in a systems change perspective (Figure 2).²⁶ Each level of the model is designed to address sources of fragmentation. The model is built on microlevel care continuum service systems to provide tailored services corresponding to linkage to care and retention in care in youth-focused HIV medical services, with transition to adult services added at an appropriate age. Care continuum service systems are embedded within meso-level youth-focused community support and treatment infrastructures. These community infrastructures represent local disease prevention and control efforts, set local priorities, and coordinate services across multiple community agencies and clinicians.²⁷ Both microlevel care continuum services and community infrastructures are embedded in a macrolevel collaboration at the level of the Department of Health and Human Services. This collaboration provides overall vision, program coordination, guidance, and resources. The model incorporates a timeline to acknowledge the differential focus of systems on various milestones along the care continuum and to capture the individual and public health relevance of elapsed time (eg, time from infection to antiretroviral therapy initiation). The model is implicitly developmental, recognizing the significant psychosocial developments of

Figure 2. An Integrated, Multilevel Model for the Human Immunodeficiency Virus (HIV) Continuum of Care for Youth



middle and late adolescence into young adulthood, reflected in potential service disjunctions as youth transition from pediatric/adolescent-focused care to adult care.²⁸ Although not depicted in the model, some milestones along the care continuum are irreversible (eg, becoming HIV positive) but others may be achieved, lost, and reached (eg, retention in care or viral suppression).²⁹

There is room for additional refinements of the model, informed by lessons learned in its initial deployment and subsequent evolution. First, a systematic and deliberative approach is needed to maintain interagency collaborations. Interagency collaborations are often top-down mandates, and ours benefitted from permissive language of the NHAS that encouraged shared, interagency leadership that continued to reflect each agency’s priorities. However, we found that collaboration needed advocates in each agency and regular formal and informal communication. Our program developed in the context of specific funding initiatives, and it remains to be seen whether the collaboration is sustained as priorities shift within respective government agencies. Modification of an existing infrastructure, eg, the Health Resources and Services Administration’s Ryan White HIV/AIDS program, could provide a focal point for interagency collaboration and for the national, community-focused, systematic implementation science needed to achieve greatest benefit from our now-substantial investments in youth-focused HIV prevention and treatment.³⁰

Second, collaborations of youth-focused linkage to care programs and local health departments are critical. Local health departments ultimately have responsibility for HIV surveillance in many jurisdictions and have long experience of community-wide infectious disease prevention through screening, case-finding, partner services, and treatment. However, local health departments vary greatly in terms of organization and authority, and many lack resources to support the

evidence-based intensive case management and patient navigator approaches used here. Partnerships with academic and local organization can address these resource limitations and are associated with improved public health performance.³¹ Public health authority was an important but not critical element of these partnerships and created significant ethical and legal challenges for some health departments.²⁰ We found that collaborations between SMILE and local health departments were important even in the absence of public health authority, sometimes leading to implementation of linkage to care protocols for the entire health department jurisdiction. Local collaborations could be additionally supported by data-sharing programs, such as those described in CDC’s Data To Care toolkit that uses HIV surveillance data to identify persons infected with HIV not in care, link them to care, and support the HIV care.³² However, ongoing development of methods for confidential information exchange between surveillance and care systems is critical to maximizing HIV treatment as prevention efforts at a community level.¹⁸

Third, our intervention was built on the planned creation of referral networks to link geographically dispersed and often disconnected testing sites to the limited number of youth-friendly sources of HIV specialty care available in most communities. Multiple, sometimes competing referral networks exist in many communities, with third-party payers able to stipulate care with select providers to the exclusion of others.³³ Implementation of the Affordable Care Act in 2014 added important options for youth linkage to care, although new challenges emerged in terms of enrollment and eligibility.³⁴ Integration of HIV-related care for youths into primary care health systems is not yet practical in most locales, suggesting the longer-term need for integrated testing and treatment strategies and providing further justification for the existence of multiagency collaborations such as ours to provide a critically needed safety net for such a vulnerable and marginalized population.³⁵

Localization of approaches to linking youths to care was an important element of the SMILE program. However, we found that approaches developed at one site were useful in others, and we found it useful to develop and enforce high levels of adherence to the intervention. This was accomplished with a National Coordinating Center that provided training and technical assistance to each site. The collaboration also benefitted from the existing clinical, community mobilization, and research infrastructure of the ATN to provide a focal point for conceptual development of the collaborations’ goals and their implementation. With that infrastructure, we implemented scientific protocols and guidance for service delivery to address specific milestones of the care continuum. These protocols provided data that will be used to evaluate the collaboration.

Conclusions

Our experience shows that an integrated, multilevel, youth- and community-focused intervention for linkage and engagement in HIV care is feasible, potentially effective, and may offer a sustainable approach to addressing age-related and other health disparities and inequities to health outcomes for youths infected with HIV.

ARTICLE INFORMATION

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Correction: This article was corrected on July 1, 2017, to correct an error in the Abstract. The Main

Outcomes and Measures portion of the Abstract should read “Cross-agency collaboration,

youth-friendly linkage to care services, community mobilization to address structural barriers to care, cooperation among services, proportion of all men who have sex with men who tested, and rates of linkage to prevention services.”

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Author Contributions: Dr Fortenberry had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Acquisition, analysis, or interpretation of data:

Fortenberry, Kapogiannis, Jeffries, Wilson.

Drafting of the manuscript: Fortenberry, Kapogiannis, Jeffries, Ellen.

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