HHS Public Access

Author manuscript

J HIV AIDS Soc Serv. Author manuscript; available in PMC 2016 May 25.

Published in final edited form as:

J HIV AIDS Soc Serv. 2016 ; 15(2): 158–179. doi:10.1080/15381501.2015.1074977.

Creating Systems Change to Support Goals for HIV Continuum of Care: The Role of Community Coalitions to Reduce Structural Barriers for Adolescents and Young Adults

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Abstract

Routine population-wide HIV screening, early linkage and long-term retention in healthcare for HIV-infected individuals are key nodes of the HIV continuum of care and are essential elements of the National HIV/AIDS Strategy. Despite this, up to 80% of youth are unaware of their HIV infection status and only 29% are linked to HIV healthcare; less than half are engaged in long-term HIV healthcare, and far fewer maintain viral suppression. To fill this gap and to address the national call to action to establish a seamless system for immediate linkage to continuous and coordinated quality healthcare after diagnosis, this paper describes the processes and mechanisms by which the SMILE Program worked within the infrastructure of the ATN-affiliated Connect to Protect® (C2P) community coalitions to address structural barriers that hindered youth in their communities from being tested for HIV infection or linked and engaged in healthcare after an HIV positive diagnosis.

Keywords

Adolescents/Young Adults; HIV Continuum of Care; Structural Barriers; Community Coalitions

INTRODUCTION

Adolescents (aged 13-19) and young adults (aged 20-24 years) in the United States (U.S.) are disproportionately affected by the human immunodeficiency virus (HIV). In 2010, they comprised 17% of the U.S. population (**1**), but accounted for 26% of all new HIV infections (**1,2**), reflecting a 25% increase in the number of cases for adolescents and a 31% increase for young adults between 2006-2009 (**2,3**). Despite the high incidence of new HIV

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infections, the percentage of adolescents and young adults that has tested for HIV infection is low. Routine population-wide HIV screening, early linkage to and long-term retention in healthcare for HIV-infected individuals are key nodes of the HIV continuum of care (CoC), and are essential elements of the National HIV/AIDS Strategy (**4**). However, only 13% of high school students and 35% of young adults, aged 18-24 years, report ever being tested for HIV (**2**). Consequently, between 60% (**2, 5**) and 80% (**6**) of adolescents and young adults are unaware of their HIV status compared with the national estimate of 16% to 20% of the 1.1 million persons living with HIV (**1,7,8**). Analyses of four large-scale trials that include adolescents and young adults indicate that 29% to 73% are linked to HIV healthcare within one year of their HIV diagnosis, but only 41% are engaged in long-term HIV healthcare, and less than six percent maintain viral suppression (**9**). Thus, a critical understanding of the barriers to HIV CoC is urgently needed in order to successfully identify undiagnosed infections and successfully link, treat and retain HIV-infected adolescents and young adults (hereafter referred to as youth) in HIV healthcare.

Barriers to HIV CoC are associated with a complex interaction of interrelated individual-level factors, including race and ethnicity (e.g., African American/black race, Hispanic/Latino ethnicity) (**10-13**); psychological factors (e.g., distress and fear concerning HIV healthcare; mistrust of the healthcare system and HIV treatment; perceived HIV stigma) (**11,14-21**); cultural factors (e.g., perceived racism, sexism, and homophobia, and language barriers) (**11,12, 15-18**), and (5) comorbid influences (e.g., mental illness, substance abuse, incarceration) (**11,15,21-23**). However, with few exceptions (**24,25**) little attention has been given to the social determinants and structural barriers that may constitute the underlying root causes of HIV CoC failure for youth. These factures include poverty and food insecurity (**15,17,26**), unemployment (**14,15**), homelessness (**17,26,27**), transportation access (**16,17,20,26**), and health insurance eligibility and policies (**13**). Interventions that address these barriers may improve HIV CoC for youth. One such approach is to identify a potentially modifiable set of structural barriers (e.g., deteriorated housing, inadequate transportation systems and limited hours at local health clinics) that exist within communities that impair achievement of the prevention and treatment objectives of the HIV CoC (**24,25,27-30**). At a community level, addressing structural barriers to the HIV CoC can be accomplished through intentional systems change initiatives designed to create adjustments in the complex network of youth-serving institutions and services associated with HIV CoC (**31**). Structural interventions developed from a systems change initiative may include a variety of approaches, including community mobilization, integration of services (in this case, HIV-related services), funding, and economic/educational interventions. They are also unique in that they target entities, not people, to make changes in programs, practices or policies and shape the community landscape to promote improved health outcomes (**29**). Despite evidence of difficulty in engaging HIV-infected youth in the HIV CoC, there are few evaluations of structural interventions focused on this age group (**32**).

In response to the National HIV/AIDS Strategy's mandate and call to action, more information from empirical research is needed to guide community strategies and seamlessly link, engage, and retain HIV-infected youth in healthcare. To address this important public health gap, the Strategic Multisite Initiative for Identification, Linkage and Engagement

(SMILE) Program was developed and implemented as a collaborative-effort between Eunice Kennedy Shriver National Institute Child Health and Development (NICHD), the CDC, and local health departments with a goal of linking all HIV-infected youth to HIV healthcare. An important element of the SMILE program is the ongoing HIV community mobilization efforts of the Connect to Protect ® (C2P) coalitions, a study supported by the Adolescent Medicine Trials Network for HIV/AIDS Interventions (**33**). C2P builds on the concept of "AIDS-competent communities" defined as collaborative support to achieve community-wide objectives such as access to HIV testing and treatment services (**34**). Six themes define AIDS-competent communities: members' skills and knowledge related to HIV and youth; enhanced dialogue where members have the opportunities to discuss HIV prevention and treatment; ownership and responsibility; confidence in local strengths that builds faith in collective efficacy for addressing HIV-related issues; and, solidarity as an outcome of effective relationships and collective successes.

Other analyses have shown how C2P coalitions have been successful in supporting AIDS-competent communities for HIV-prevention among youth (**35**). A central focus of C2P is the identification of local social and structural factors that impede HIV prevention in youth, such as poor shelter options for displaced youth and inadequate access to youth and lesbian, gay, bisexual and transgender (LGBT)-competent health care providers. C2P coalitions have addressed these types of issues by advocating for new or modified policies or practice changes within citywide systems, such as departments of health, education or juvenile justice. However, key elements of the HIV CoC for youth – HIV testing, linkage to care and retention in care – were not initially incorporated into the coalitions' planning efforts.

Thus, the purpose of this paper is to describe the extension of the C2P model to address these elements and illustrate the types of system-focused structural changes that are achievable to improve clinical outcomes for HIV-infected youth. Where possible, specific agency outcomes and markers showing improved opportunity for HIV care are provided. As we seek to marry the goals of the National HIV/AIDS Strategy with contextual factors that influence clinical care outcomes for youth, this formative work is critical to our understanding of how communities can work collaboratively to adopt structural changes that will optimize HIV-infected youths' potential to link, engage and be retained in long-term medical care.

METHODS

The ATN is a National Institutes of Health clinical research network comprised of 14 Adolescent Medicine Trials Units (AMTUs) located in Tampa and Miami, FL; Los Angeles, CA; the District of Columbia; Philadelphia, PA; Chicago, IL; Bronx, NY; New Orleans, LA, Memphis, TN, Houston, TX, Detroit, MI; Baltimore, MD; Boston, MA and Denver, CO. Each AMTU initiated a local C2P coalition that was charged with the primary goal of achieving structural changes targeting community-level HIV risk. Since 2006, the C2P coalitions have collectively achieved more than 300 structural changes defined as new or modified programs, policies or practices that either directly or indirectly influence youth and are sustainable without the C2P coalition's ongoing involvement. In 2010, the SMILE Program was initiated at nine of the AMTUs and in 2012 an additional five AMTUs were

launched. Each AMTU had a dedicated linkage-to-care (LTC) Coordinator who was funded to link HIV-infected youth to medical care and to assist with C2P coalition activities.

C2P Model

The C2P model is based on the Community Empowerment Framework (**36**) that broadly defines "the process of gaining influence over conditions that matter to people who share neighborhoods, workplaces, experiences, or concerns." It emphasizes seven factors for successful coalition development and function, including: (1) defining a clear vision and mission; (2) strategic planning; (3) coalition leadership; (4) providing resources to mobilizers; (5) documentation of coalition efforts and feedback on progress; (6) technical assistance; and (7) making outcomes matter (**37**). The C2P approach uses the power of community stakeholders to bring about structural changes that would be difficult for any single organization to achieve independently (**38**).

Coalitions are comprised of diverse community members including health care providers, school administrators, social service managers, government officials and youth. C2P coalitions have a range of 10-35 regular members and typically meet every two months with subcommittee meetings occurring during the alternating month. Each C2P coalition has one paid staff member referred to as the C2P Coordinator. An administrative body, the National Coordinating Center (NCC), provides central study oversight and ongoing training and technical assistance to C2P and LTC Coordinators and coalitions.

Root Cause Analysis to Identify Structural Changes

Root cause analysis (RCA) is embedded within the C2P strategic planning framework and provides a problem-solving process for coalitions to examine underlying factors that contribute to HIV risk in the community and tie those factors to system-level structural changes using a series of prompting questions (**39**). RCA shifts the focus away from individual-level behavior and emphasizes conditions in the community that become targets for change, which was a critical method for coalitions to use in thinking about structural interventions targeting systems. A logic model diagram facilitated coalition planning by visually depicting the objectives developed and how they related to the six core risk factors linked to HIV acquisition (i.e., number of sex partners, high-risk sex partners, and sex partner concurrency) and transmission (i.e., condom/clean needle use, sexually transmitted infection (STI) co-infection, and viral load)(**40**).

Using Local Data and Experiences to Guide HIV CoC System Changes

Coalitions utilized data that were available on a monthly basis via the SMILE program to gain a clearer understanding of the youth who were in need of HIV medical services and the issues they experienced in trying to obtain healthcare such as transportation needs and documentation requirements. Several steps were needed to prepare coalitions for addressing these barriers via structural changes, including: formation of a linkage to care (LTC) subcommittee within each C2P coalition, nomination of a subcommittee chair (often the LTC coordinator shared this role with another coalition member); trainings and resources provided by the NCC to LTC coordinators on structural change concepts; and, where needed, the recruitment of new coalition members with clinical or administrative experience

pertaining to HIV healthcare and treatment. Moreover, some C2P coordinators used additional methods to build local coalition capacity related to CoC issues, including inviting guest speakers from the health department to discuss the state of HIV testing, linkage and engagement among youth in their respective city, and touring local HIV testing facilities to meet with staff and clients to learn first-hand about barriers they encountered. The LTC coordinators provided ongoing updates to the C2P coalition about their experiences while working with HIV-infected youth.

Data Analysis

The study team reviewed existing study records to assess SCOs that were achieved along the HIV CoC. Records included Action Plan Worksheets that each C2P coordinator entered into the study database to indicate the initiation, completion, revision or discontinuation of a SCO and a C2P logic model, which was a table that C2P coordinators maintained to identify how the SCO addresses HIV risk for youth. This document helped the study team categorize SCOs along the HIV CoC. For completed SCOs, members of the team followed up with C2P and LTC coordinators by telephone to identify outcomes reported by the entity implementing the change. Finally, minutes from coalition meetings were reviewed to assess the types of partners and actions taken by coalition members as they worked on each SCO.

RESULTS

As of September 2014, all but one C2P coalition has developed a LTC subcommittee. The coalitions have initiated 240 SCOs related to HIV CoC for youth within their communities. These SCOs focused on structural barriers to HIV CoC, including HIV testing (48%), linkage (41%), engagement and retention (11%) in HIV healthcare, and viral suppression (0.4%); 127 (53%) of the SCOs have been completed (i.e., identified and enacted solutions to address structural barriers). Many other SCOs are currently underway, but have not been actualized, including efforts supporting engagement and retention in HIV healthcare. Specifically, six LTC subcommittees are working to create seamless and coordinated healthcare systems, including youth-friendly navigation programs, improved transportation, establishment of transitional services and in-house services for a “one stop shop” for healthcare and social services. Five coalitions are working on improving resource allocation for homeless youth and five are dedicating efforts toward improving cultural competency of service provision for local youth. Although a majority of the SCOs were initiated to directly address barriers to HIV CoC for youth, others were identified by the coalitions and through the LTC coordinators’ direct efforts with clients; several others were the result of NCC-facilitated cross-sharing between sites that were experiencing similar issues. Table 1, provides a brief description of a subsample of the barriers that were identified and structural changes that were achieved by the LTC subcommittees across the AMTUs. Below we feature five C2P coalitions (Memphis, TN, Miami, FL, Tampa, FL, New Orleans, LA, and Los Angeles) that have implemented SCOs for which impact has been identified.

Connect to Protect Coalition in Memphis, TN

The C2P Memphis coalition has been addressing LTC barriers since 2011. Their LTC subcommittee meets monthly and has approximately seven active partner agencies,

including the Memphis Health Center, Shelby County Health Department, University of Memphis, Methodist LeBonheur Healthcare System, Shelby County Schools' Coordinated School Health, Church Health Center and Christ Community Health Services. Members are health department officials, medical case managers, social workers and mental health professionals from various healthcare and testing agencies within their jurisdiction. The subcommittee is co-chaired by the SMILE LTC coordinator and the Assistant Deputy Director of the Shelby County Health Department. The LTC coordinator, who is highly respected and interacts routinely with youth in the community, is able to facilitate and attend both medical and non-medical appointments (e.g., eligibility, housing, food stamps), thus building strong rapport in support of her clients' total well being. She brings barriers identified through her work with clients to the subcommittee for discussion and strategizing about potential SCOs. Since its inception, the LTC subcommittee has initiated 26 SCOs to improve systems and ensure linkage to care of newly diagnosed youth. Fourteen of the SCOs have been completed. SMILE program data presentations are a standard part of the larger coalition meeting agenda to ensure integration and continued capacity building of members.

Several issues identified through the LTC subcommittee are reported in Table 1, two of which already have reportable impact and are described here. The first was the lag time in reporting of HIV positive cases by a major blood bank to the Shelby County Health Department, which resulted in significant lost to follow up of new diagnosis. Specifically individuals diagnosed with HIV infection at the local blood banks were appearing in the health department's database approximately six months after their confirmatory result. Investigation of this issue uncovered several systemic barriers between identification and linkage to care. These included the blood bank's lack of established procedures for follow-up with cases and their lack of capacity to handle a new diagnosis. The C2P Memphis LTC subcommittee worked with the Interstate Blood Bank and the Shelby County Health Department to implement three SCOs: (1) a new practice by Interstate Blood Bank of immediately reporting (i.e., as soon as identified) all HIV positive clients to the Shelby County Health Department for follow-up, (2) Interstate Blood Bank revised their HIV notification letter to reflect clear and established instructions on how patients should contact the Shelby County Health Department for linkage and engagement into medical care, and (3) The Shelby County Health Department formalized partnership with the SMILE Program for immediate referrals of all identified HIV-infected youth aged 12-24 years for linkage and engagement into medical care. To date, the lag time between identification of an HIV positive test result and reporting to the local health department has been substantially reduced from an average of six months to within one week of the specimen collection date. Additionally, 17 newly identified HIV-infected youth have self-reported to the Shelby County Health Department in response to a notification letter from the Interstate Blood Bank.

A second issue identified by the LTC coordinator was an unusually low report of HIV incidence from private providers. A further assessment revealed that although required by law, a number of private physicians and health centers that conduct HIV tests for youth were not routinely reporting results to the local health department. Additionally, many providers cited the lack of capacity to link youth to appropriate healthcare as a reason for not testing. As reported in Table 1, a number of SCOs were initiated and completed within various

private health care systems. Most notably, within the first month of establishing a policy that required healthcare personnel (i.e., residents, private physicians, social workers, etc.) to immediately refer HIV-infected youth to appropriate youth linkage to care staff, eight new HIV infected youth from the Methodist LeBonheur Healthcare System were identified and linked to medical care. Prior to SCO implementation, an average of two to three clients were referred annually to the local health department.

Connect to Protect Coalition in Miami, FL

The C2P Miami coalition has been addressing linkage to care barriers since 2006, prior to the launch of the local SMILE program. The coalition, consisting of 27 community partners, does not have a formal LTC subcommittee; therefore, SCOs that target barriers along the HIV CoC are subsumed within action plans of the other subcommittees. Coalition members lead subcommittees that meet monthly. The coalition's membership comprises representatives from diverse systems and sectors (e.g., Florida Department of Health, foster care, Miami Dade County Public Schools, HIV education, healthcare, and testing agencies) that are able to offer insight and perspective around various aspects of their strategic plan. The LTC coordinator shares SMILE Program data as well as barriers identified through her work to support the development of HIV testing and linkage to healthcare SCOs. To date, the C2P Miami coalition has initiated 21 SCOs, 10 of which have been completed. A structural barrier that was identified and brought to the coalition by the LTC coordinator, was the Ryan White proof of income eligibility requirement, which prevented newly identified HIV-infected youth who were accepting LTC services from being linked to care in a timely manner. With the C2P coalition's support, the Miami-Dade County Office of Grants Coordination enacted a policy change in 2011 affecting their Ryan White Program Service Delivery Guidelines (Section 7.1 A (2)). The amended policy exempted minors (aged 12-17 years) and young adults (aged 18-25) with HIV/AIDS from providing income eligibility documentation. This barrier was identified by the coalition in 2010 and was completed in July 2013. As a result of the completed SCO, the percentage of cases reported to the SMILE Program that were accepting LTC healthcare services, but who were not linked decreased from 25% in February 2013 to 9.5% in January 2014.

Connect to Protect Coalition in Tampa, FL

In 2012, the C2P Tampa coalition established a LTC subcommittee to consider and address linkage to care barriers for youth. The subcommittee, which meets monthly, has a membership of 10 to 12 active participants representing key stakeholders from several healthcare and testing agencies (e.g., the County's Health Department, Ryan White Care Administration and Council, Tampa Bay Crisis Center, and the local AIDs Education and Training Center). The subcommittee is co-chaired by the SMILE LTC and C2P coordinators. Since its inception, the LTC subcommittee has initiated 39 SCOs. Of these, 28 have been completed.

Cross sharing of information facilitated by the NCC enabled the C2P coalition to adopt the Ryan White Income Eligibility policy change that was implemented in Miami. Starting with Hillsborough County's Health and Human Services Ryan White Administration they obtained exemption of income eligibility documentation for minors (aged 12-17 years). With

this change approved, the coalition reached out to the Family and Aging Services Ryan White Care Administrator that serves both Hillsborough and Pinellas Counties, for exemption of income eligibility documentation for young adults (aged 18-26). Since the Affordable Care Act enables young adults to be covered under their parents' health plans through age 26, this change was also approved in 2013. Seven other counties in the state of Florida that are not affiliated with the ATN subsequently adopted the combined change that impacted both minors and young adults.

Connect to Protect Coalition in New Orleans, LA

The C2P New Orleans coalition established a dedicated LTC subcommittee in 2012 to address barriers to HIV CoC for youth. Co-chaired by the Program Monitor of the Office of Health Policy and AIDS Funding and the Patient Navigator of Louisiana State University's Outpatient Clinic, the subcommittee comprises 11 active members that represent school-based health centers, the criminal justice and juvenile justice systems, Unity for the Homeless and other healthcare and testing agencies. The subcommittee, which meets monthly, has a diverse strategic plan with several SCOs in the education, medical and criminal justice sectors that address efforts to improve linkage and engagement to HIV-related care for youth. Since its inception, the subcommittee has initiated 22 SCOs related to the HIV CoC, eight of which have been completed. As a highly respected member of the community, the LTC coordinator serves as the eyes and ears of the youth, reporting barriers and challenges confronted by youth back to the coalition for possible development of SCOs. The LTC subcommittee has also informally engaged HIV-infected and at risk youth through focus groups as a strategy to obtain their input about new areas and issues that are preventing youth access to medical care. For example, within the Louisiana Juvenile Justice System (JJS), the LTC subcommittee identified that there were missed opportunities to test and diagnose at risk adolescents who were being detained. JJS staff did not have the proper training to appropriately link HIV positive youth to healthcare, which prevented HIV testing from being initiated. In response, the C2P coalition identified and advocated for two complementary SCOs: (1) HIV/STI testing for all youth upon intake into the JJS Youth Study Center, and (2) establishment of a formal healthcare referral process to link HIV-infected youth to healthcare who are identified at the JJS Youth Study Center. The coalition was able to gain buy-in from the Center's superintendent who recognized the importance of implementing more HIV testing and healthcare within this sector. The superintendent subsequently supported and approved implementation of both SCOs. As of March 2014, the impact of these SCOs has resulted in three newly identified HIV positive adolescents who were successfully linked to HIV healthcare within the Louisiana JJS.

Connect to Protect Coalition in Los Angeles, CA

Since its inception in 2006, the C2P Los Angeles coalition has been addressing LTC barriers through a Care and Testing subcommittee. The subcommittee's action plan of SCOs addresses a wide array of barriers from transportation and mental health issues to incarceration and stigma associated with being HIV infected. This subcommittee meets monthly and has approximately five to 10 active partner agencies, including Planned Parenthood, Department of Health, St. Johns Well Child and Family Center, Children's Hospital, and REACH LA. The SMILE LTC coordinator serves as content expert, bringing

information about LTC barriers for discussion and strategizing as well as creating opportunities for community capacity building (e.g., with launch of the local SMILE Program, she spearheaded an LTC Provider Tour to reengage/educate the community about youth linkage to care issues). Since its inception, the subcommittee has initiated 25 SCOs to improve HIV testing for at-risk youth and linkage to healthcare for HIV infected youth. Sixteen of the 25 SCOs have been completed.

One recent example of an issue brought to the subcommittee by the LTC Coordinator was that HIV-infected youth were not receiving their medications upon entry and/or release from the detention center. These youth were returning home or to a group home without their medications, which has implications for viral suppression. The subcommittee worked with the Los Angeles County Probation Department to establish internal guidelines regarding post incarceration placement of HIV-infected youth. The SCO accomplished in January, 2014 ensures that no matter where HIV-infected youth have encounters within the system, they will be connected to a linkage worker and receive their antiretroviral medications. This change, which originally targeted the Barry J. Nidorf Juvenile Hall, has been instituted at all 22 juvenile detention facilities in Los Angeles County. Subsequently as an indirect result of these efforts the Los Angeles County Probation Department has required that social workers at all facilities complete HIV101 and an LGBT cultural competency education as part of their initial training process.

DISCUSSION

Youth in the U.S. are disproportionately impacted by the HIV epidemic with alarmingly high rates of new HIV infections diagnosed annually (**1**-**3**,**5**). Moreover, we have become increasingly aware of the role that local policies and practices have in influencing the health outcomes of HIV positive youth, as well as the power of communities to modify existing systems (**48**). We have described the processes and mechanisms by which the ATN-affiliated C2P community coalitions mobilized to address structural barriers that hindered youth in their communities from being tested for HIV infection or linked and engaged in healthcare when they receive an HIV positive diagnosis. Specifically, we have demonstrated that the C2P community coalitions that are comprised of a committed group of local volunteer stakeholders, decision makers, and content experts can effectively work together to bring about locally identified structural changes related to HIV prevention (**33**,**44**-**47**). Unique to this effort was the role of the LTC subcommittees within the C2P coalitions engaged in strategic planning leading to HIV CoC structural changes to remove barriers that hindered HIV-infected youth from linking to, remaining engaged in, and being retained in long-term HIV healthcare. As noted, the LTC subcommittees' activities are ongoing, but clear and compelling strides have been made with 240 SCOs focused on barriers to HIV CoC for at risk and HIV-infected youth in their communities. Of these, 114 (53%) have resulted in solutions that addressed the identified barriers. As noted, structural changes have been enacted to address HIV testing practices in youth detention facilities, reporting of routine testing practices among private healthcare providers, HIV case reporting practices in a local blood bank facility, health service delivery practices for adolescents and young adults, and polices related to healthcare eligibility for HIV-infected adolescents and young adults (see Table 1). An unexpected finding from changes made to the Ryan White insurance eligibility

policy was the adoption of this change extended to other non-ATN affiliated counties through cross sharing of information spearheaded by the NCC. This outcome, in particular, highlights ways in which community mobilization efforts that utilize the power of local community members (e.g., stakeholders, decision makers, and experts) by leveraging their collective knowledge, skills, and expertise could have a powerful impact in ways that would be difficult to accomplish by any individual or single organization.

CONCLUSIONS

In essence, C2P is an established, systematic entity within each ATN community reflecting principles of community-based participatory research. It is based on scientific principles of capacity building and community mobilization strategies and provides the infrastructure for translating research into practice. Importantly, C2P utilizes a protocol-driven approach in which C2P coordinators convene coalitions of power brokers, decision-makers and stakeholders to identify and implement structural changes to reduce barriers to HIV prevention and healthcare continuum. Through strategic planning, identification, and enactment of SCOs, C2P is creating a repository of replicable community practices that have the potential to impact health outcomes along the HIV CoC. The C2P infrastructure, including C2P coordinators, the LTC coordinator, and the NCC, provides a means for standardizing focus, activities, and metrics for monitoring influences on HIV CoC within and across all ATN-affiliated AMTUs. While C2P benefits from a strong infrastructure, with systems and procedures in place, many of the policy and practice changes described here can be accomplished through local cross-systems collaboration. At a local level, a mutual desire for improved HIV CoC outcomes, open communications, creative problem-solving and community capacity-building, big-picture thinking and awareness of community-wide resources are some of the key elements that are needed to achieve similar community practices in other locales. Lastly, although our findings to date have primarily impacted linkage to care outcomes, the existing C2P infrastructure will enable continued examination of SCOs that may further impact engagement in care, retention in care, and viral suppression. We expect to report these findings in a subsequent paper.

ACKNOWLEDGEMENTS

The Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) is funded by grants 5 U01HD40533 and 5U01HD40474 from the National Institutes of Health through the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) (Bill Kapogiannis, MD, Sonia S. Lee, PhD) with supplemental funding from the National Institutes on Drug Abuse (Richard Jenkins, PhD, Katherine Davenny, MPH) and Mental Health (Susannah Allison, PhD, Pim Brouwers, PhD). Additional support was provided by an administrative supplement awarded through funds from the American Recovery and Reinvestment Act (ARRA) of 2009. The authors would like to acknowledge our collaborators from the Centers for Disease Control and Prevention (Linda Koenig, PhD). We also thank the Connect to Protect® (C2P) Community Coordinators and SMILE Linkage to Care (LTC) Coordinators, in the cities featured, for their support and insights: Andrea L. Williams MPH, and Brooke Askew, MHSA (St. Jude Children's Research Hospital), Kenia Sanchez, MSW and Grechen Mills, BS (University of Miami-Miller School of Medicine), Cristian Chandler, MPH and Michelle McKinney, BS (University of South Florida), Nadrine P. Hayden, BS and Trina Jean Jacques, MSW (Tulane University Health Science Center) Milton Smith, BA and Raenisha Brown, LCSW (Children's Hospital of Los Angeles). We are grateful to the Principal Investigators of the participating AMTUs and their entire staff for their contributions to this project, including Patricia Emmanuel, MD, Diane M. Straub, MD, Marvin Belzer, MD, Lawrence D'Angelo, MD, Steven Douglas, MD, Jaime Martinez, MD, Lisa Henry-Reid, MD, Donna Futterman, MD, Sue Ellen Abdalian, MD, Lawrence Friedman, MD, Patricia, Flynn, MD, Aditya Gaur, MD, Mary Paul, MD, Elizabeth Secord, MD, Allison George Agwu, MD, Renata Arrington-Sanders, MD, Kenneth Mayer, MD, Elizabeth J. McFarland, MD and Daniel Rierden, MD. We appreciate the scientific review provided by members of the Community Prevention Leadership

Group of the ATN. We are grateful to the ATN Coordinating Center at the University of Alabama for their network, scientific and logistical support (Craig Wilson, Principal Investigator, Cynthia Partlow, MEd, Project Director) and to the ATN Data and Operations Center at Westat for their network operations and analytical support (James Korelitz, PhD, Principal Investigator, Barbara Driver, RN, MS, Project Director). Technical assistance, training and protocol support was provided by the National Coordinating Center at Johns Hopkins University. We are indebted to members of our community coalitions for their commitment and dedication to this work, and to the SMILE LTC Coordinators, and C2P Community Coordinators for their passion and devotion to helping at-risk and HIV-infected youth in their communities and for their overall contributions to the project's implementation.

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TABLE I

HIV Continuum of Care (CoC) Structural Change Objectives (SCOs), Solutions, and Impact on At Risk and HIV-infected Youth

CoC Node	Issue/Barrier	SCO Solution(s)	Impact/Outcomes to Date
HIV Testing/Diagnosis	Missed opportunities to identify and diagnose at risk youth detained in the Louisiana Juvenile Justice system (JJS)	The Louisiana JJS implemented HIV/STD screening of youth upon intake at the Youth Study Center, their New Orleans area facility	Three new HIV-infected youth were identified and linked to HIV medical care within the first year after implementation of the linkage to care (LTC) SCO at the Louisiana JJS Youth Study Center facility.
Linkage to Care	The JJS lacked capacity to appropriately handle HIV positive diagnoses	The Louisiana JJS's Youth Study Center facility subsequently established a formal linkage to care referral process to link identified HIV positive youth into care	
	Lack of appropriate follow-up (with donor) and major lag time between identification and public health reporting to the local Department of Health (LHD) by a major blood bank resulted in known HIV-infected blood donors becoming lost to follow	Interstate Blood Bank began a new practice of immediately referring (as soon as identified) all HIV-infected clients to the Shelby County Health Department	Reduced average referral time (from Blood bank to LHD) from six months to within one week of specimen collection date
		The Shelby County Health Department began a new practice of immediately referring newly identified HIV-infected youth to the LTC Coordinator for linkage and engagement into medical care	SCO-related activities are ongoing
		Interstate Blood Bank had revised the HIV notification letter to donors to reflect clear and detailed instructions on how to engage with the Shelby County Health Department for linkage and engagement into medical care	Since implementation of this SCO, 17 new HIV-infected individuals have self-reported to the Shelby County Health Department in response to the HIV notification letter
	Lack of LTC procedures for school-aged youth	Denver Health School-based Health Centers adopted Denver Health's Linkage to Care practices and Clinical Guidelines for HIV Screening in Colorado	This change affects 16 school-based health centers in Denver
	Limited health care coverage for HIV-infected youth	The Los Angeles County established screening protocols that were used by Ryan White Care providers to establish eligibility for appropriate health care coverage options including Healthy Way LA	SCO-related activities are ongoing
	Lack of youth friendly patient navigators to support seamless linkage to care	OraSure Technologies instituted a new policy in which the SMILE LTC Coordinator is listed as contact for individuals ages 13-24 with HIV positive tests seeking medical care and/or have questions about their results	This structural change affects youth linkage to care in 13 urban cities across the country
	Presumptive HIV positive youth identified in the Emergency Department were referred to adult care clinics and therefore they were less likely to receive healthcare follow-up	The Detroit Receiving Hospital Emergency Department instituted a new policy to inform the referral of presumptive HIV positive youth that were tested within the Emergency Department directly into medical care	SCO-related activities are ongoing
	Known HIV-infected juvenile detainees were lost to healthcare follow upon release from juvenile detention centers due to a lack of transitional medical care polices	The Miami-Dade Regional DJJ developed and implemented a practice of linking HIV-infected detainees upon their release to an HIV medical facility, including the transfer of medical records	SCO-related activities are ongoing

CoC Node	Issue/Barrier	SCO Solution(s)	Impact/Outcomes to Date
		Bay Point Schools, Inc. developed and implemented a practice of linking HIV infected residents upon their release to an HIV medical facility, including the transfer of medical records	SCO-related activities are ongoing
		The Miami Dade County Juvenile Service Department (JSC) developed and implemented a practice of linking HIV-infected detainees, upon their release to an HIV medical facility, including transfer of medical records	Three HIV-infected youth were identified and linked to care since implementation of this SCO
	The absence of routine reporting and LTC by Private Providers	A local physician established a new policy to ensure that HIV tests results, for youth (aged 13-24), who test HIV positive at her office, are provided to LTC staff to ensure follow-up and direct linkage to care services	One newly identified HIV infected youth was reported/referred within the first two months of SCO implementation
	Although required by law, a number of youth serving agencies (including private physicians and Health Centers) that conduct HIV tests were not routinely reporting results to the LHD	The Methodist LeBonheur Healthcare System established a new policy that requires referring personnel (i.e., physician residents, private physicians, social workers, etc.) ensure that results for youth (aged 13-24) who test HIV positive are provided to LTC staff. This will ensure follow up and direct linkage to care services	Eight new HIV-infected youth aged 13-24 years were reported to the Memphis SMILE Program for linkage to youth-specialized HIV medical care with two moths of SCO implementation; previously it was two-three referrals per year
	Many healthcare providers lacked capacity to link to youth appropriate medical care	St. Francis Hospital System established a new policy that required referring health providers (i.e., Residents, Private Physicians, Social Workers, etc.) to ensure that results for youth (aged 13-24) who test HIV positive linked to LTC staff to ensure follow up and direct linkage to medical care	SCO-related activities are ongoing
		Delta Medical Center established a new policy that requires referring personnel (i.e., physician residents, private physicians, social workers, etc.) ensure that results for youth (aged 13-24) who test HIV positive are provided to LTC staff. This will ensure follow up and direct linkage to care services	SCO-related activities are ongoing
		The Church Health Center established a new policy that requires referring personnel (i.e., physician residents, private physicians, social workers, etc.) ensure that results for youth (aged 13-24) who test HIV positive are provided to LTC staff. This will ensure follow up and direct linkage to care services	SCO-related activities are ongoing
	Ryan White proof of income eligibility requirement prevented newly identified HIV positive youth who were accepting LTC services from being linked to care in a timely manner	The Miami-Dade County Office of Grants Coordination enacted a policy change amending their Ryan White Program Service Delivery Guidelines, FY 2010-2011 under Section 7.1 A (2) “Documentation of the client's economic status that establishes their gross household income”, exempting minors (aged 12-17) and young adults (18-26) with HIV/AIDS from providing income eligibility documentation	The percentage of cases reported to SMILE that were “Accepting LTC services but not linked” decreased from 25% in to 9.5% within one year
		The Hillsborough County Health and Human Services Ryan White Administration also amended their Ryan White Program Service Delivery Guidelines, FY 2009-2012 exempting minors (aged 12-17) with HIV/AIDS from providing income eligibility documentation	Structural changes were adopted in Tampa and replicated in seven other counties (i.e., Hernando, Pasco, Pinellas, Manatee, Polk, Hardee, Highlands Counties) that were not ATN affiliated
		Family and Aging Services Ryan White Care Administrator for Hillsborough and Pinellas amended their Ryan White Program	

CoC Node	Issue/Barrier	SCO Solution(s)	Impact/Outcomes to Date
		service delivery guidelines FY 2009-2014 exempting dependent young adults (aged 18-26) with HIV/AIDS from providing income eligibility documentation	
	Lack of transportation result in missed medical appointments affecting linkage to care.	The Baltimore City Health Department began providing free transportation to the first two medical appointments for newly identified HIV positive youth or those that have been out of care for six months or more, identified through the SMILE Program and eligible for Ryan White Services	SCO-related activities are ongoing
Engaged/Retained in Care	Lack access to youth-friendly services for engagement and retention	The Adolescent AIDS Program at the Children's Hospital at Montefiore created a new policy to extend their clinic hours	SCO-related activities are ongoing
	Lost to follow after first medical care appointment	The Adolescent AIDS Program at the Children's Hospital at Montefiore created a new policy for clinicians to follow a protocol scheduling newly diagnosed patients for a second appointment within two weeks of their first appointment	SCO-related activities are ongoing
	Other life circumstances are deemed (food security) more important than adherence to medical care	Fair Foods began to provide two bags of fresh food daily, if needed, for youth living with HIV in the Boston area	SCO-related activities are ongoing
	Lack of transportation results in missed medical appointments and affect long term care	The Hubway Bike System through the City of Boston's, Boston Bikes program, began a new practice of providing an annual membership pass to HIV-infected youth who are eligible for government assistance through the SMILE program. This practice provides the youth with an additional form of transportation, that will help overcome transportation barriers as well as aid in healthier living in the Boston Metro Area	SCO-related activities are ongoing
	HIV-infected youth are not retained in healthcare (i.e., become lost to follow) as they transition to adult care settings that do not specifically focus on youth needs	The Institute for Public Health Innovation (IPHI) established a youth navigation program to aid HIV-infected youth to transition to adult healthcare in the Washington, DC area	SCO-related activities are ongoing
	Lack of staff competence in patient related policies and procedures resulted in patient lost to follow	The Detroit Health and Wellness Promotion's (DHWP) Ryan White Part A Program had amended their program site visit tool to contain an additional section that assesses line staff's knowledge of policies and procedures that pertain to the patients	SCO-related activities are ongoing
Viral Suppression	HIV-infected youth incarcerated were not receiving medications upon release from the detention center (i.e., they returned home or to a group home without their medications)	The Los Angeles County Probation Department developed internal guidelines regarding post incarceration placement of HIV positive youth within the system.	This SCO impacts all 22 juvenile detention facilities in LA county
		This SCO ensures seamless healthcare linkage medication access for all HIV-infected by linking them to a LTC worker	Based on this change the Los Angeles County Probation Department subsequently implemented a new policy requiring that social workers at all facilities complete HIV 101 and LGBT cultural competency training as part of their on-boarding