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## Linking HIV+ adolescents into care: The effects of relationships between local health departments and adolescent medicine clinics

Amanda E. Tanner, PhD, MPH<sup>1</sup>, Morgan M. Philbin, MHS<sup>2</sup>, Mary A. Ott, MD<sup>3</sup>, Anna DuVal, MPH<sup>4</sup>, Jonathan Ellen, MD<sup>4</sup>, Bill Kapogiannis, MD<sup>5</sup>, J. Dennis Fortenberry, MD, MS<sup>3</sup>, and The Adolescent Trials Network for HIV/AIDS Interventions

<sup>1</sup>Department of Public Health Education, University of North Carolina Greensboro, Greensboro, NC

<sup>2</sup>Department of Health, Behavior & Society, Johns Hopkins School of Public Health, Baltimore, MD

<sup>3</sup>Department of Pediatrics, Indiana University School of Medicine, Indianapolis, IN

<sup>4</sup>Department of Pediatrics, Johns Hopkins School of Medicine, Baltimore, MD

<sup>5</sup>Pediatric, Adolescent and Maternal AIDS Branch, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, Bethesda, MD

### Abstract

**Background**—The fragmentation of HIV-related diagnostic and treatment services, especially for youth, is a significant barrier for transitioning to care. The study identified key elements that affected care linkage efforts.

**Methods**—We conducted 64 interviews across 15 clinical sites. The constant comparative method was used.

**Results**—Primary linkage to care processes are illustrated through three geographically diverse case studies. Factors included: inter-agency relationships, data sharing protocols, and service duplication concerns. Program improvement strategies were discussed.

**Conclusions**—A strong, citywide network is helpful in coordinating care linkage services. These partnerships will be critical in effectively realizing the goals of the National HIV/AIDS.

### Keywords

Adolescents; HIV; Linkage to care; health departments

### Introduction

Linkage to care for HIV-infected persons refers to a systematic process of initiation of medical, psychological and social services for those newly diagnosed. Linkages that result in sustained engagement improves health outcomes among HIV-infected individuals (McCoy et al., 2009; Mugavero et al., 2012; Ulett et al., 2009) but is complicated by the physical transition of patients that is needed when individuals are tested in settings other than those providing clinical care. Additionally, linkage to care often requires information transfer

across one or more institutional boundaries (e.g., testing organizations to health departments). Poorly coordinated diagnostic and care systems, with different funding streams for testing and care, contribute to service fragmentation that is a significant barrier to the National HIV Strategy goal of “seamless” transitions from HIV diagnosis into care (Mugavero et al., 2011; Office of National AIDS Policy, 2010; Penner & Leone, 2007; Tanner et al., 2010).

HIV-infected youth may be especially likely to fail in linkage to HIV care because of individual characteristics (e.g., stigma and shame, denial, low educational achievement, substance use, psychiatric disorder), family characteristics (e.g., lack of health care insurance, family dysfunction, past and current neglect/abuse) or concerns about the HIV health care system (e.g., costs to patients, services available, access, the degree of “youth-unfriendly” staff and services) (Hosek, Harper, & Rocco, 2000; Hosek et al., 2008; Kang, Goldstein & Deren, 2006; Mallinson et al., 2005; Mill et al., 2008). Improvements in linkage to care are possible (e.g., the CDC-sponsored Antiretroviral Treatment Access Study II [ARTAS II]), however, these studies were limited to adults aged 18 years and older (Gardner et al., 2009; Gardner et al., 2005) and may not be address the unique challenges adolescents face (e.g., disclosure to parents through insurance needs).

Implementation of “test-and-treat” HIV-control strategies has resulted in more youth needing linkage to HIV-related care (IOM, 2010). Recent results from expanded health care provider HIV testing initiatives indicate that a higher percentage of individuals diagnosed in clinical settings are linked to care, as compared to community-based testing organizations (CDC, 2011). These factors highlight the importance of local health departments in coordinating the community linkage to care efforts, including the coordination of screening (a core public health surveillance function [IOM, 2010]) and clinical care. In addition, health departments are responsible for national data reporting (e.g., HIV incidence) and comprehensive treatment and care for HIV positive individuals, including mental health and dental services (NASTAD, 2008). Care provision also serves a core public health function in that risk of HIV transmission is reduced in appropriately treated patients. Health departments can facilitate communication between testing and treatment providers with the provision of public health authority, which allows the sharing of individual level client data (e.g., contact information) (Craw et al., 2010).

Explicit partnerships between health departments and testing and care agencies would allow for more effective efforts to link newly infected adolescents to care (Craw et al., 2010; Craw et al., 2008). However, the extent to which health departments and agencies can coordinate linkage to care efforts for adolescents has not been sufficiently examined. This study identified key elements that affected local care linkage efforts through the implementation of an adolescent linkage to care program. A better understanding of these relationships could assist in coordination of health departments with testing and care organizations to create a more efficient linkage to care process for HIV infected youth.

## Methods

The Strategic, Multisite Initiative for the Identification, Linkage and Engagement in Care of Youth with Undiagnosed HIV Infection was designed to facilitate the linkage to care process for newly diagnosed HIV-infected adolescents with linkage to care defined as an HIV-related medical visit within 42 days of referral. The program was developed within a formal collaboration between the National Institute for Child Health and Human Development (NICHD), Centers for Disease Control and Prevention (CDC), and the Adolescent Medical Trials Units (AMTU) of the Adolescent Medicine Trials Network for HIV/AIDS Interventions. The AMTUs are located in 15 clinical sites across the US (housed in

academic medical centers), and provide comprehensive HIV-related care for adolescents aged 13 – 24 years. The AMTU are often the primary adolescent-specific HIV care providers in their respective cities, and served as primary clinical care sites for the program.

The primary program objective was to improve formal partnerships between the AMTU and local health departments. Each AMTU, in partnership with its local health department, developed a memorandum of understanding to describe the linkage to care process, specify provision (if any) of public health authority to the program staff, and specify sharing (if any) of patient-related data. Thus, health departments were directly involved in specifying the implementation of the program at each site, but were not involved in the overall program design or evaluation. Each AMTU was provided with financial support for a full-time linkage to care outreach worker to provide linkage to care services and to build relationships with other agencies serving adolescents with HIV.

As part of the program evaluation, we interviewed AMTU staff involved in the program, including outreach workers, nurses, case managers, and physicians. Open-ended interview questions explored site-specific linkage to care processes, inter-organizational relationships, and program scale-up. Interviews were digitally recorded, transcribed verbatim, and managed using Atlas ti 6.2 (Muhr, 2004). Average interview length was 68 minutes (range=32-118 minutes). The Institutional Review Boards at the Johns Hopkins Medical Institutions and all AMTU sites approved study protocols.

The primary data source was interview transcripts, analyzed using the constant comparative method (Glaser & Strauss, 1967). A coding dictionary was created based on existing literature, interview questions, and preliminary readings of transcripts. Particular attention was given to AMTU-health department relationships, the process of linkage to care, data transfer, and the role of the outreach worker in the linkage to care process. A random sample of 33% of interview transcripts was cross-coded by a second coder to confirm the initial coding structure. Analytical memos were written to summarize the codes. Memos were used to structure discussions of the memos by the two coders, and codes were refined into initial themes based on these discussions (Glaser & Strauss, 1967). Transcripts were then searched for negative cases to identify exceptions to the initial themes; codes were modified as needed, with returns to the data for additional comparisons (Glaser & Strauss, 1967). We then used a comparative case-analysis approach (Eisenhardt, 1989; Glaser & Strauss, 1967) to identify representative sites that highlighted the primary linkage to care approaches. The finalized coding structure was applied to all transcripts by one researcher; a random sample of 20% of interviews was re-coded by a second researcher. Initial independent codings were compared and indicated high consistency among raters (87%) and discrepancies were resolved by discussion.

Comparisons across all 15 sites identified three general approaches to the AMTU-health department partnerships that formed the basis of the program. In case-comparison analysis, the selection of cases that represent the full range is encouraged (Pettigrew, 1988). Thus for each approach, we selected one site that exemplified that linkage to care based upon the following characteristics: AMTU-health department collaboration, data sharing protocols (including public health authority) community linkage to care infrastructure, and utilization of the outreach worker. In addition, efforts were made to select cases from geographically diffused locales as unique state/local policies may affect the linkage to care process. The comparative case-analysis approach (Eisenhardt, 1989; Glaser & Strauss, 1967) allowed for a description of how preexisting professional relationships affected the three different AMTU-health department partnerships, and in-turn, how these AMTU-health department relationships influenced approaches to avoid service duplication and improve linkage to care. Each site contributed 4-7 interviews, for a total of 16 interviews included in this

analysis. The interviewees included: seven ATMU program staff (e.g., outreach workers), five mental health providers (e.g., social workers), and three medical providers (e.g., physicians). Of these interviewees, 12 were women and 4 were men.

## Results

Across the three representative cases, program implementations differed by prior health department collaboration and existing AMTU-health department/community agency relationships, granting of public health authority and data sharing, solutions to avoid duplication of services, and general approaches to the linkage to care process. Table 1 compares sites across these key areas.

### General linkage to care process

Sites differed markedly in the general linkage to care processes in terms of access to data about tested adolescents, and level of interaction with newly diagnosed adolescents (Figures 1-3). Site A established a protocol for face-to-face meetings of the program outreach worker and a newly diagnosed adolescent at the point of diagnosis (see Figure 1). The outreach worker assessed readiness for care, provided information about HIV clinic visits, scheduled appointments, and maintained contact until the clinic visit occurred. This early, active interaction with the outreach worker assisted in developing relationships with the adolescents and streamlined the linkage to care process.

In contrast to the direct interaction of the outreach worker and adolescents, Site B implemented the program by using the outreach worker largely for surveillance of linkage to care (see Figure 2). The outreach worker was connected to an array of existing resources to ensure that the adolescents were linked to care by maintaining contact with other agencies' staff, identifying areas of difficulty, coordinating resources to these areas, and in general coordinating linkage to care processes in the city. In lieu of working directly with the youth, the outreach worker used data provided by the health department to determine whether and when adolescents had been linked to care. The monitoring role was aided by the outreach worker's physical presence at the health department. A primary goal of developing a surveillance program was to ensure sustainability: "I think our model can be sustained, because it essentially will teach the Health Department how to do this work." (Site B)

Similar to Site A, Site C's linkage to care protocol worked to facilitate early, direct contact with adolescents (see Figure 3). However, Site C implemented the program with much less direct support from its health department, and agency-specific protocols had to be developed for each referring test site. Site C also emphasized assessment of readiness to care, and availability of the outreach worker for direct provision of support, including accompanying adolescents to first clinic visits. However, interactions with adolescents were hampered by lack of access to data and lack of an overall process to monitor success of linkage to care efforts.

### Relationships

The program implementation at Sites A and B was substantially facilitated by existing inter-agency collaborations and relationships, additionally supported by former health department employees as program staff. The program also worked to strengthen existing ties.

... I think it [relationship with health department] has improved... There's always been a relationship with them. I just feel like this [program,] has definitely been more collaborative. You know, so they know us better and they know better what we can do and what we can offer. We're getting to know them better too. (Site B)

These sites actively cultivated health department relationships and worked to ensure that the health department benefited from engagement in the program.

We went in saying, “This is what we have to offer, can you help us too?” And that's always been the approach, and I think that's helped a lot of people to kind of relax to say, “Oh, they're not just asking, but they're actually offering too.” (Site A)

The relationship of Site B and the health department was particularly strengthened by physically locating the program outreach worker within the health department. Although role definitions and relationships with case managers were initially difficult to define, this strategy allowed for direct participation of the outreach worker in a range of health department activities related to linkage to care.

In contrast to Sites A and B, Site C implemented the program with the health department limiting the number of agencies with which AMTU staff could interact. This limitation was not originally specified in the memorandum of understanding created between AMTU and health department.

These MOU's [memoranda of understanding] got created, and then when we approached the agencies to have the MOU signed, to talk about the programs, talk about how we would fit in, they never had heard of us. So everything stopped at the health department and nothing ever trickled down. (Site C)

### **Public Health Authority and Data Sharing**

A required element of each memorandum of understanding was an explicit statement addressing the granting (or not) of public health authority by the health department to the program staff. Full public health authority was granted in some sites (exemplified by Site A), with explicit denial of public health authority in other sites (exemplified by Site C). Informants saw the provision of public health authority as a clear facilitator of information transfer, of the ability to link adolescents to care, and of follow-up for adolescents who did not engage in care. Site C received only quarterly aggregate data from the health department, which was not useful for linkage to care activities of the program.

Site B's public health authority was limited to monitoring purposes only, as the outreach worker did not directly provide linkage to care services or have direct youth contact. Testing agencies reported all HIV-related information to the health department, with the outreach worker contacting reporting agencies to ensure that adolescents had been linked to care. However, the outreach worker was situated within the health department, facilitating communication with referring agencies and improving data transfer to the health department.

### **Service Duplication**

Service duplication referred to the perception that the AMTU program linkage to care services already existed, either within the health department itself or through partnerships with other community organizations. Sites with a history of strong relationships with their health departments were able to directly address the potential for duplication and create an understanding of benefits of the program to the health department. In Site B, where the AMTU outreach worker was directly embedded in the health department, service duplication was addressed by careful negotiation of roles:

Because otherwise, yes, we would be [duplicating services], but what we're doing is following standard Department of Health procedures of an existing system... She's [the AMTU outreach worker] acting as an agent of DOH when she's making those referrals, because any of their staff could make these referrals. (Site B)

A common theme across sites was the observation that duplication of services was a form of service fragmentation, and that without some form of central coordination, competition for referrals could perpetuate such fragmentation.

I do see that territorial issue when it comes to actual service provision...they [organizations] get funded to provide HIV services, and so they were under the impression that [the AMTU outreach worker] job was to meet a young person at a [community-based testing] clinic and take them to [AMTU clinic], and they were like we don't want to do that because then you're screwing up with the funding source, and it took us a while to get them to understand that we just want [the AMTU outreach worker] to meet that young person and make sure that they link—we don't care where they link, we just want to make sure that they do. (Site C)

## Discussion

The National HIV/AIDS Strategy repeatedly emphasizes the importance of “seamless” linkage to care for newly diagnosed, HIV-infected persons (Office of National AIDS Policy, 2010). However, the fragmentation of HIV testing and care works against such seamlessness (Mugavero et al., 2011). The cases presented illustrate three factors, including relationship characteristics, communication processes, and data sharing protocols, where health departments are key components in linkage to care for adolescents. First, linkage to care is affected by the relationships of health departments (responsible for HIV testing and surveillance in most communities) and specialized HIV care providers. Health departments could play an important role in coordinating services to improve linkage to care rates, especially for those who are tested in non-clinical organizations, where linkage to care rates are lower (CDC, 2011). However, it is unclear to what degree health departments systematically incorporate specific plans for linkage to care into local mandates for HIV surveillance, as recommendations for expanding HIV testing often include only generic references to linkage to care. The health department policies may be particularly important in rural areas where scarcity of resources and distance between testing and care sites may further limit the provision of HIV services, especially those specific to adolescents.

Second, active communication by health departments can assist in connecting testing and care facilities and reducing service duplication. As funding policies are beginning to require that HIV testing programs have linkage partners, the potential for service duplication will continue (Mugavero et al., 2011). A more collaborative approach used in some sites aligns with existing research that notes: “collective actions can be strengthened by bringing together partners that share similar vision or services...it is also the people who bring the resources to the common community table, along with the combination of personalities, agency dynamics, and political agendas involved that can move a coalition to either success or failure” (Straub et al., 2007). The structural requirement of partnerships of health departments and AMTU care providers was an important element of the AMTU program and provides a useful model for a more general national approach to linkage to and engagement in care for HIV-infected adolescents.

Finally, health departments have an important role in facilitating appropriate information transfer that allows proactive, system-driven linkage to care rather than patient-driven care seeking. Health departments have a clear responsibility to maintain the confidentiality of HIV-infected adolescents. However, the exercise of public health authority may aid linkage to care by directly integrating testing and care systems. This is particularly important as HIV testing venues are likely to remain dispersed in communities (to facilitate access) while HIV care facilities are often focused to only a few within a given area (to concentrate resources and expertise).



## Study limitations

These data should be evaluated in the context of particular limitations of the research. Given the breadth of the AMTU clinical sites we used a comparative case approach to present three cases to concisely highlight the range (but not complete details) of the linkage to care processes (Pettigrew, 1988). Recognizing that there are opportunities for various program conceptualizations to fit within specific community infrastructures is important for other locales as they move forward with their linkage to care efforts. In addition, we relied solely on the perspectives of AMTU program and clinical staff, without speaking directly to health department staff. Future efforts should include health department staff as their unique insight into barriers and facilitators of linkage to care generally, and related to data sharing, will be important for continued improvement in linking adolescents infected with HIV to care. Although local health departments were notified of the AMTU program via our collaborators in the Centers for Disease Control & Prevention, each health department had complete latitude in the form of its participation. This means that a great deal of additional work is needed to understand the most efficient processes for comprehensive involvement of health departments in linkage to care efforts to decrease service fragmentation.

## Conclusion

A strong network within a given city aids in structuring an efficient linkage to care model to avoid service duplication concerns and decrease fragmentation of services to promote the health of HIV-infected adolescents (Mugavero et al., 2011; Straub et al., 2007). Partnerships of health departments and HIV care clinics are needed to fully support a seamless transition from HIV testing and diagnosis to HIV-related care (Craw et al., 2008; Straub et al., 2007) especially for overcoming the unique barriers faced by HIV-infected youth (Phibin et al., under review). Implementation of enhanced testing initiatives has heightened the need for a more developed set of tools for linkage to care. These tools could include: an assessment of best practices, development of models for better integration of screening/testing and care organizations, individual-focused tools for assessment of readiness for care engagement, and provider education to improve retention in care. At the federal level, grantors, including the CDC and NIH, can play an important role in facilitating the collaboration between clinics, health departments, and community agencies, including support for use of public health authority and tools for data sharing. These approaches will be a critical foundation to effectively realizing the goals of the National HIV/AIDS Strategy for vulnerable youth populations, with HIV, in this country.

## Acknowledgments

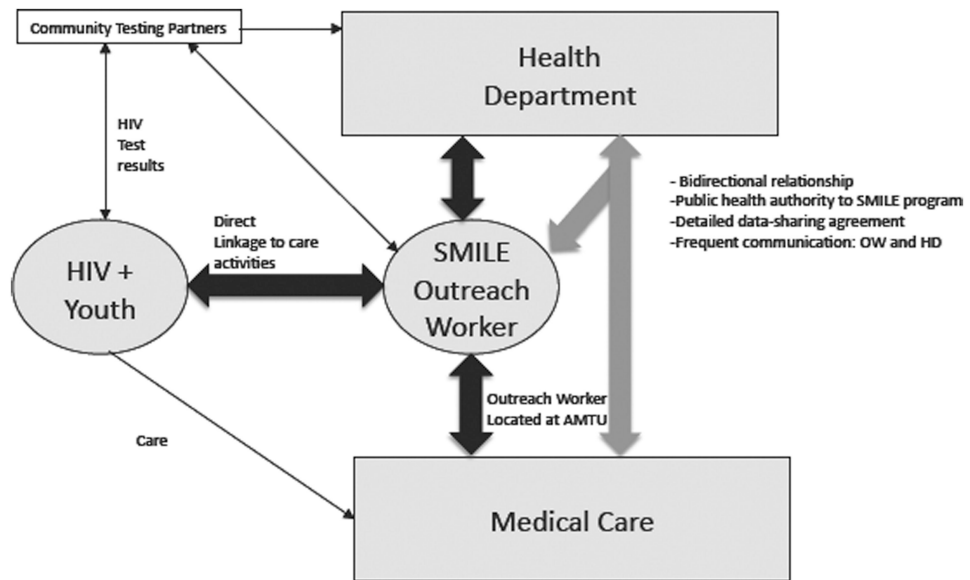
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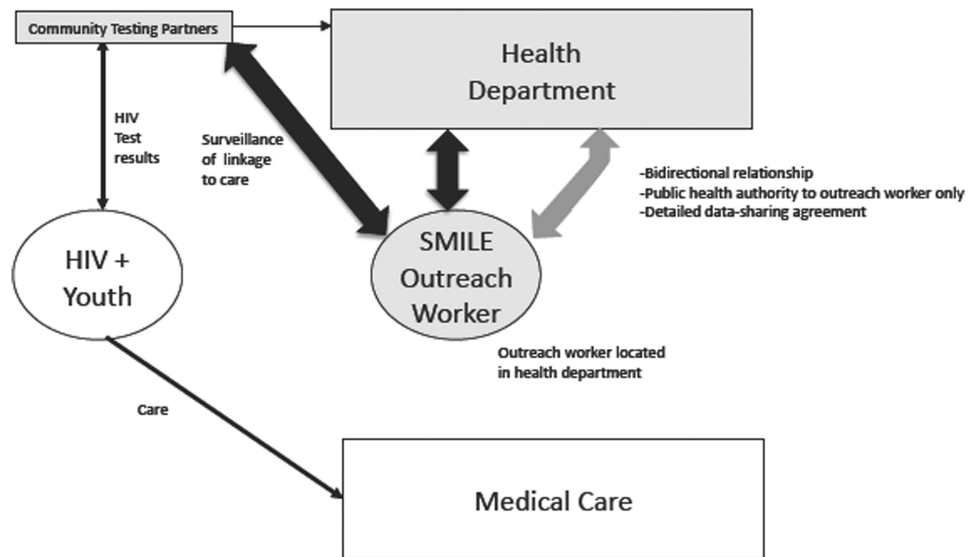
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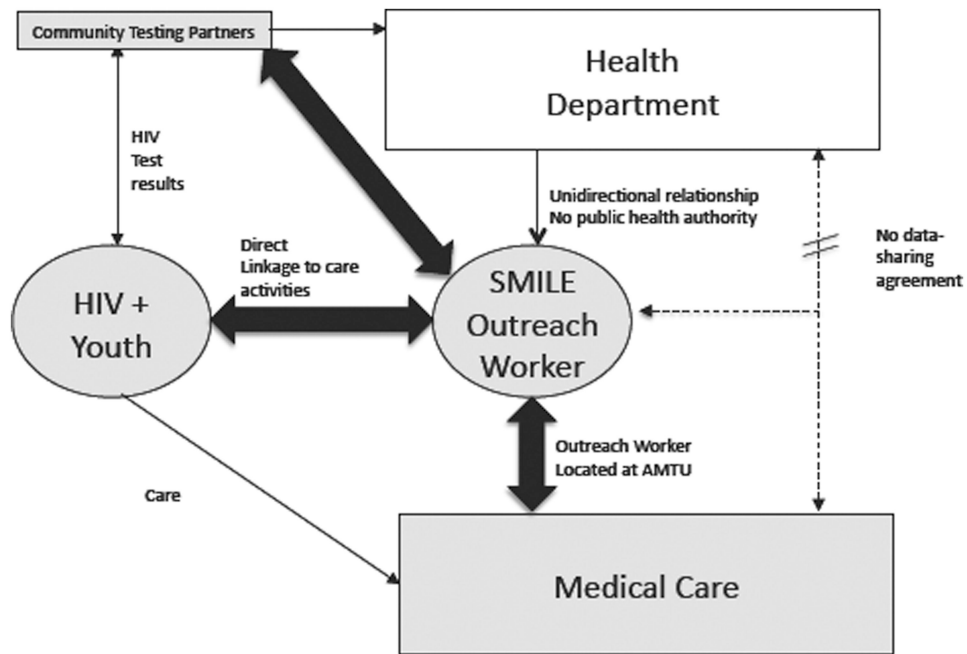




**Figure 1.**  
Site A program conceptualization.



**Figure 2.**  
Site B program conceptualization.



**Figure 3.**  
Site C program conceptualization.

**Table 1**  
**Comparison of key program concepts across sites**

Program elements	Site A	Site B	Site C
Relationships of AMTU-Health Department	Prior collaboration; Physical space in health department for outreach worker; Frequent communication	Prior collaboration; Physical space in health department for outreach worker; Daily communication	Limited prior collaboration; No direct association with health department; Infrequent communication
Public Health Authority	Yes	Yes, restricted to outreach worker	No
Data Sharing Agreement	Individual level data; outreach worker can	Individual level data; outreach worker cannot contact youth directly	Aggregate data from health department (no contact information)
Means of Addressing Potential Service Duplication	Reduced by direct communication	Addressed by defining surveillance role of outreach worker	Health department specified limits of partnerships with referring agencies
General linkage to care process	Outreach worker receives information from health department; contacts youth directly and works directly with organizations	Outreach worker directly incorporated into health department; no direct youth contact	No direct information from health department; direct contact of outreach worker with youth; organization specific linkage to care protocols