

HIV prevention interventions with adolescents: Innovations and challenges in partnerships across the integrated transitions model

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Abstract:

In the USA, the incidence of HIV is rapidly increasing among young people. To increase the effectiveness of HIV prevention and care, efforts for adolescents should consist of interdisciplinary partnerships that address the complexity of the population and co-occurring physical and mental health issues. Partnerships among academic researchers; representatives from educational and testing organizations, health departments, clinics, and other community-based organizations (including youth-serving organizations); and adolescents themselves are essential. These partnerships can produce innovative strategies that address adolescent-specific issues related to HIV prevention, diagnosis, and care, as well as cultural norms and gender-role expectations particular to adolescents, their developmental stage, and their local communities. Such partnerships can also increase understanding during exploratory and formative evaluation phases, inform the development of interventions and programs that are most relevant to adolescents, and increase the likelihood that these interventions and programs will be implemented, found to be effective, and sustained (if warranted) by communities. Some academic researchers, clinicians, and other providers partner directly with adolescents, while others partner with youth-serving organizations to engage and work with adolescents.

In this chapter, we use the *integrated model of continuities and transition in adolescent/youth HIV prevention, diagnosis and treatment and the care continuum* to illustrate innovative adolescent HIV prevention interventions and programs that engage adolescents and representatives from community organizations, incorporate partnerships, and promote community participation along a continuum. Specifically, we explore two types of partnership strategies—youth-engaged and organization-engaged. We provide an overview of the phases of the integrated model and associated programs with (and without) partnerships with adolescents and community organizations. We conclude with lessons learned and directions for future community-engaged research, interventions, and programs for primary and secondary HIV prevention with adolescents.

Keywords: Adolescent | Intervention | HIV-positive | Care continuum | Youth-serving organization | Diagnosis | Treatment | Prevention | Antiretroviral therapy

Book Chapter:

The period of adolescence, defined by the Society for Adolescent Health and Medicine as ages 10–25-years old [1], involves immense physical, biologic, and cognitive changes, including rapid maturation, experimentation, and risk [2]. Provision of health care for adolescents remains challenging and complex, as it encompasses general medical needs and factors specific to cognitive and psychosocial developmental phases. Accordingly, adolescent medicine emerged as a subspecialty of pediatrics to address many of the developmental issues and social needs unique to adolescence [3, 4]. A purely physiologic approach is insufficient for comprehensive adolescent health; instead, a psychosocial, holistic orientation that maximizes adolescent development and health is necessary to address the complexities that characterize adolescence [3]. Adolescents must manage new physical and emotional challenges, maintain healthy bodies, and learn skills and responsibilities needed for adulthood (e.g., obtaining jobs).

The physical, emotional, and social changes typical of adolescent development also can heighten their risk of HIV exposure and transmission [2]. For instance, the developing adolescent brain can limit what some may label as responsible decision-making, thereby increasing sexual risk behaviors without the adolescent fully considering longer-term consequences [2, 5]. Thus, HIV-related research and intervention and program development, implementation, and evaluation must consider adolescent-specific issues such as brain development (e.g., abstract thinking skills), assent and consent (e.g., being under 18-years old and parental consent), insurance (e.g., public and parents'), and disclosure (e.g., to parents and to current and potential sexual partners) [6, 7]. Interventions and programs must further be tailored to the contexts and communities in which adolescents live.

In the USA, the incidence of HIV is rapidly increasing among adolescents and young adults 15–24-years old [2]. Approximately 56,300 Americans become HIV-positive each year; of these, 34 %—or approximately 19,000—are 13–29-years old [8]. In 2009, an estimated 8,294 adolescents and young adults between 13- and 24-years old were diagnosed with HIV infection in the 40 states with long-term HIV reporting [9].

High rates of HIV among adolescents, coupled with the typical developmental processes of adolescence, suggest that HIV-prevention efforts are essential for both adolescents at risk for HIV acquisition and those who have HIV [2]. Primary prevention interventions focus on preventing HIV exposure and transmission to uninfected adolescents to keep them negative and increase their self-protective behaviors and skills [10, 11]. These types of interventions can take various forms, including biomedical approaches such as clinical trials to evaluate HIV-preventive vaccines, microbicides, and preexposure prophylaxis and behavioral methods to increase condom use and reduce numbers of partners [10]. Secondary prevention serves to minimize, alleviate, or prevent health and psychological consequences among adolescents with HIV [11] and examine behavioral and therapeutic interventions, ideally at earlier stages of infection, to prevent disease progression [10]. Secondary prevention can also be designed to preserve both the health of adolescents with HIV and the health of their potential sexual partners,

including test-and-treat initiatives [12] and disease management strategies such as earlier initiation of antiretroviral therapy (ART) [10].

Both primary and secondary HIV-prevention and -care efforts for adolescents should consist of interdisciplinary collaborations that address the complexity of the population and comorbidities, as well as mental, psychiatric, and neurocognitive disorders [10]. Partnerships among academic researchers; representatives from educational and testing organizations, health departments, clinics, and other community-based organizations (including youth-serving organizations); and adolescents themselves are essential. These partnerships can encourage innovative strategies that address adolescent-specific issues related to HIV prevention, diagnosis, and care, as well as cultural norms and gender role expectations particular to adolescents, their developmental stage, and their local communities. Such collaborations can increase understanding during exploratory and formative evaluation phases, inform the development of interventions and programs that are most relevant to adolescents, and increase the likelihood that interventions and programs will be implemented, found to be effective, and sustained (if warranted) by communities. Prevention programs may benefit from partnerships between academic researchers, clinicians, and other providers and youth-serving organizations to address the substantial adolescent-specific barriers that they may experience, including their feeling invincible to HIV (or perhaps more precisely a willingness to “play the odds”), discomfort communicating about sexual issues, unfamiliarity with care systems, and limitations with transportation [13, 14, 15]. Some academic researchers, clinicians, and other providers partner directly with adolescents, whereas others partner with youth-serving organizations.

In this chapter, we use the *integrated model of continuities and transition in adolescent/youth HIV prevention, diagnosis and treatment* [16], and the care continuum [17] to illustrate innovative adolescent HIV-prevention interventions and programs that engage adolescents and representatives from community organizations, incorporate partnerships, and promote community participation along a continuum. Specifically, we explore two types of partnership strategies—youth- and organization-engaged—throughout this chapter. First, we provide an overview of the model’s phases and associated programs with (and without) partnerships with adolescents and community organizations. We conclude with lessons learned and directions for future community-engaged research, interventions, and programs for primary and secondary HIV prevention with adolescents [11].

Integrated Model and Care Continuum: An Overview

The *integrated model of continuities and transition in adolescent/youth HIV prevention, diagnosis, and treatment* (referred to as the integrated model; [16]) provides a framework for understanding the relationships between adolescents and HIV infection and highlights the importance of partnerships across networks. This model moves from primary HIV-prevention services through testing and care, and promotes consideration of the specific needs of adolescents both before and, if necessary, after HIV exposure and transmission (Fig. 1). The progression of adolescents through the integrated model is used within this chapter to highlight their unique vulnerability to HIV and potentially reduced access to services, factors that are particularly important, given that adolescents comprise a significant proportion of those with HIV in the USA.

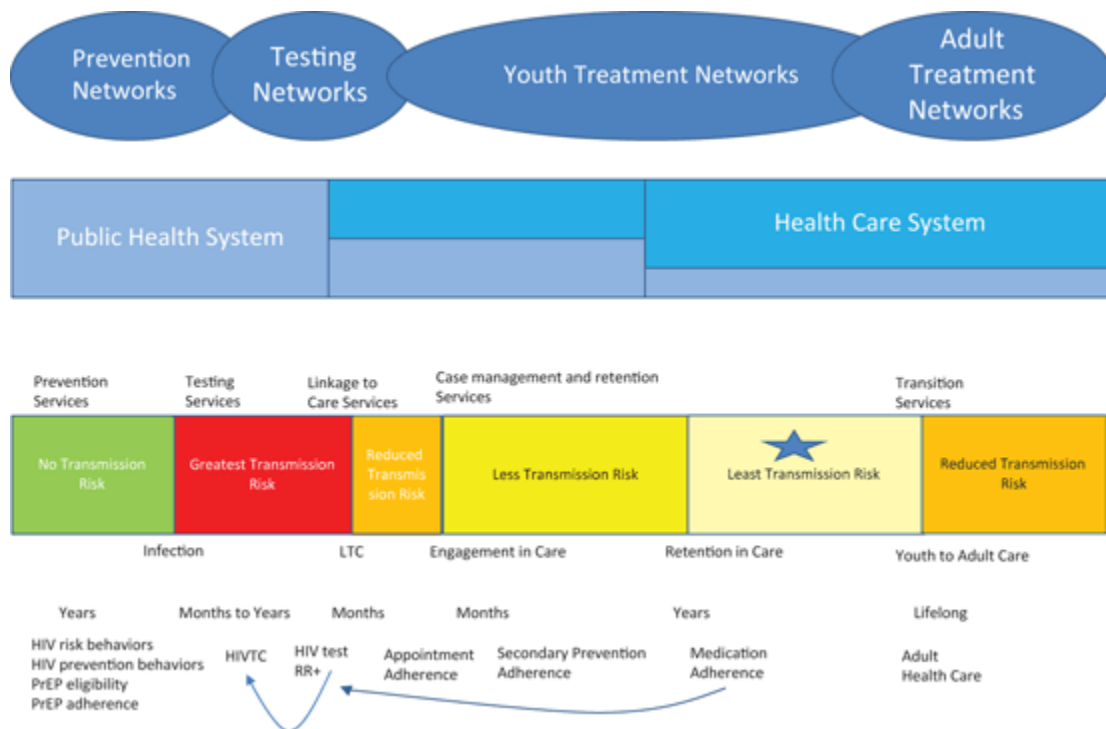


Fig. 1. An integrated model of continuities in transition in adolescent/youth HIV prevention, diagnosis, and treatment. *PrEP* Pre-exposure prophylaxis, *HIVTC* HIV testing and counseling, and *RR+* Rapid results are positive

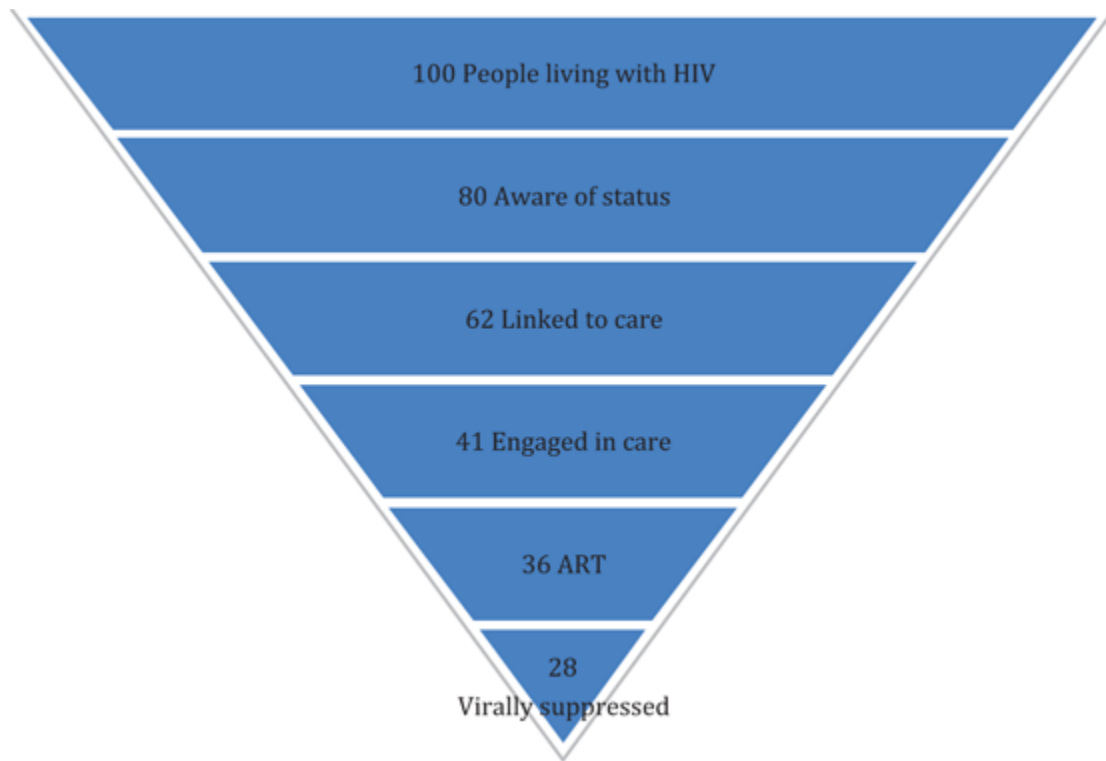


Fig. 2. Care continuum. (Adapted from Garnder et al. 2011)

Furthermore, the ongoing narrative in the USA regarding gaps in addressing the HIV and AIDS epidemic needs to consider the care continuum [17]. Generally, the steps in the care continuum include [1] the identification of HIV status, [2] active linkage in care, [3] initiation of ART, [4] retention in care, and [5] eventual suppression of viral load [17]. The care continuum also offers a way to visualize the number of individuals with HIV throughout the country and their rates of attrition as they move from being identified to getting therapy to having stable undetectable viral loads. In 2011, CDC scientists analyzed HIV surveillance datasets and laboratory reports to estimate the number of HIV-positive people at each step of the care continuum (Fig. 2; [18]). CDC scientists concluded that for every 100 individuals living with HIV, 80 were aware of their status, 62 had been linked to HIV care, 41 were engaged in HIV care, 36 received ART, and of those, 28 had achieved viral suppression (beneficial for both improved health quality and decreased transmission capability; [17]).

Providers, policymakers, and representatives from organizations across all levels—federal, state, and local—use the care continuum to identify gaps in service delivery across the continuum of HIV testing and care, and thus identify opportunities for well-designed and focused interventions and programs. The care continuum also highlights the work that needs to be done for retention in care to improve quality of life for individuals living with HIV and for population-level reductions in the incidence of HIV.

Together, the integrated model and care continuum provide an innovative, useful, and comprehensive framework for considering the challenges of identifying and treating adolescents with HIV. Rates of infection and attrition are partially due to both developmental and structural barriers that exist for adolescents across all the phases of the integrated model and, if positive, the care continuum.

For primary prevention services, adolescents may not feel at risk for HIV acquisition, in part because of their developmental stage (e.g., feeling invincible or “playing the odds;” [2]). Similarly, adolescents with HIV may find it difficult to acknowledge their disease because they do not feel sick and thus do not seek out testing to confirm their status [14]. Attending medical appointments may be perceived as a reminder of their serostatus, which adolescents may choose to avoid [14]. Adolescents with associated comorbidities (e.g., substance use, mental health issues, and housing instability) are especially unlikely to be linked to needed HIV care [9]. Other barriers to HIV testing and care include the following [19, 20, 21, 22, 23, 24, 25]:

- Individual characteristics (e.g., stigma, shame, and denial regarding HIV and risk behavior, low educational attainment, and psychiatric disorders)
- Family characteristics (e.g., lack of financial resources and/or medical/health insurance, family dysfunction, and past and current neglect/abuse)
- Health care system characteristics (e.g., costs to patients, services available, access, mistrust of health-care professionals, concerns about confidentiality, and difficulty negotiating complex health-care systems)
- Provider and treatment characteristics (e.g., shortage of providers with expertise in both HIV and adolescent medicine, the extent of adolescent-friendly staff and services, and complexity of medical regimens, although regimens are becoming simpler).

These potential barriers differ from those for adults because adolescents are often still in school and tend to be dependent on others for resources, insurance, transportation, and access to clinics and pharmacies [26]. This dependence on others such as family members, for example, requires disclosure of HIV risks and/or status, which may have potential benefits (e.g., social support), but disclosure also can place adolescents at risk for backlash and ostracism [27]. The rates of retention, medication adherence, and health outcomes are poor for adolescents diagnosed with HIV, making it especially important to keep them from being exposed to HIV and becoming positive.

Prevention, testing, and care networks must collaborate in order for adolescents to avoid HIV infection or, if infected, to move seamlessly across each stage of the integrated model (Fig. 1) and through the care continuum (Fig. 2). Although adolescents have been successfully engaged in multiple types of research, intervention, and programmatic efforts—for instance, education [28], physical activity and healthy eating [29], and violence [30]—adolescent engagement in HIV prevention is more limited [31, 32]. The available HIV-prevention efforts have demonstrated two types of partnerships that have been most successful: academic researchers, clinicians, and other providers partnering directly with adolescents or partnering with community- and faith-based organizations that serve youth (e.g., churches and organizations working with lesbian, gay, bisexual, and transgender [LGBT] adolescents and homeless adolescents). We explore these two types of partnership strategies—youth- and organization-engaged—throughout this chapter.

Integrated Model: Phases and Programs

The integrated model describes the different points of transition for adolescents' needs related to primary prevention, testing, and care that emphasizes secondary prevention (e.g., treatment as prevention; [16]). These phases of the integrated model and interventions and programs associated with each phase are described here. Some of these programs involve youth and/or organizational engagement ; the programs presented also provide an overview of adolescent HIV prevention across a range of needs, highlight the importance and challenges of working with adolescents , and provide strategies for developing engagement and partnership.

Preventing HIV Among Adolescents

Overview

Prevention often takes the form of outreach and education to identify and increase awareness among adolescents at higher risk for HIV acquisition. Adolescents at elevated risk for HIV include ethnic and sexual minorities [8, 9]. In 2010, African-American/black adolescents accounted for 69 % of HIV diagnoses reported among individuals 13–19-years old, and Latino/Hispanic and white adolescents accounted for 15 % and 14 %, respectively [33]. Among male adolescents 13–19-years old, approximately 91 % of all diagnosed HIV infections stem from male-to-male sexual contact [8]. Indeed, adolescent men who have sex with men (MSM) between the ages of 13–24 were the only age-group to have an increase in new infections between 2001 and 2006 [2]. In 2009, adolescent MSM accounted for 27 % of total incident cases, and MSM 13–29-years old accounted for 69 % of new HIV infections [9]. There is also an

interaction between race and sexual orientation; 63 % of all adolescent MSM 13–24-years old with HIV infection in 2009 were African–American/black, followed by white (18 %) and Latino/Hispanic (16 %; [8]) .

Although any adolescent can acquire HIV, particular attention should be given to these so-called hidden or hard-to-reach adolescents [34, 35, 36] to ensure that efforts have an impact and address the needs of those at higher risk of HIV exposure and transmission. Of course, being considered hidden or hard-to-reach is purely subjective; most often these terms describe being difficult to reach by community outsiders (e.g., academic researchers, clinicians, and other providers).

Primary prevention for adolescents who are at higher risk for HIV acquisition is also increasingly complex due to a range of factors, including comorbidities, such as substance use and mental-health issues, that increase the risk of HIV exposure and transmission [36]. Such complexities reinforce the importance of meaningful prevention. The integration of substance use and mental health services into HIV prevention can be an important step in reaching those adolescents at elevated risk [37].

As illustrated, HIV disproportionately affects specific adolescent population subgroups, which implies that prevention programs must address their unique issues, needs, and priorities, including perceptions of risk and substance use and abuse [38]. This need emphasizes the importance of research and programmatic partnerships (e.g., a social service organization that provides counseling services). Accordingly, a variety of partnership strategies have been employed to prevent HIV exposure and transmission among higher risk adolescents. Again, these include working directly with adolescents or indirectly through youth-serving organizations.

Youth-engaged Partnerships

A variety of primary prevention programs involve adolescents , sometimes as full partners. Adolescents participate in these programs by recruiting other adolescents, developing suitable materials, assessing the cultural appropriateness of the programming, and implementing the program.

Within these youth-engaged partnerships that include academic researchers; representatives from educational and testing organizations, health departments, clinics, and other community-based organizations (including youth-serving organizations); and adolescents, different strategies have been employed in HIV prevention . For example, a rural HIV-prevention study used participant-driven recruitment to reach and recruit adolescents living in rural upstate New York [32]. The study used peers who built trust and recruited their adolescent peers to participate in an intervention. An important component of peer recruitment, in rural and urban areas , is the inclusion of adolescents from varied and diverse population subgroups [39]. Partnering with adolescents from different backgrounds can be more effective for reaching a broad spectrum of higher-risk adolescents . This inclusivity can also serve to sustain and further partnership efforts [32, 39].

Adolescent partners also inform the development and design of appropriate methods and materials. In the HIV-prevention study just noted, a pilot group of nine adolescents developed

the educational sessions and modified the research protocols and questionnaire to reflect the context and language of local adolescents [32]. Their involvement in the design and implementation of the study enhanced their familiarity with, and commitment to, the research and its process and success. Their engagement was further validated by posters presenting the themes garnered from design and implementation discussions that illustrated for adolescent partners' concrete contributions to the study. Two members of the pilot group were later involved as paid research assistants to plan and facilitate survey and educational sessions, assist with data interpretation, and coauthor a journal article about the study. These varying levels of research opportunities and involvement contributed to the success of the study, given that adolescents were treated as significant and nontoken partners. This involvement may have motivated them to recruit other young people to participate. The inclusion of adolescent partners in this study helped reach segments of the rural adolescent population that would not have been reached and engaged otherwise, thereby contributing to its success [32].

Organization-engaged Partnerships

Another strategy academic researchers, clinicians, and other providers apply to engage adolescents, especially those at higher risk for HIV, is the formation of partnerships with youth-serving organizations, including community-based organizations working with LGBT or minority racial/ethnic communities and faith-based organizations. Prevention efforts that are delivered in partnership with specific organizations can be important vehicles to disseminate sensitive but accurate information. For example, faith-based organizations have helped reach African-American/black adolescents, which is essential given the disproportionate impact of HIV on this population [33]. Similar to youth-engaged programs, organization-engaged partnerships can facilitate successful recruitment, development and implementation of culturally congruent interventions and programs, and intervention sustainability. Providing sexual health training to organizational leaders, as part of the co-learning within partnerships, can enhance sustainability through building the capacity of community- and faith-based organizations to address HIV in their own communities, particularly with the support of trusted community partners [13, 40, 41, 42, 43].

For some minority populations, community-based organizations have played an important role in the delivery of HIV-prevention services [44]. One prevention intervention, SHERO (a female-gendered version of the word "hero"), was developed, implemented, and evaluated by a collaboration of academic researchers and representatives of a Latino-serving organization. This intervention addressed the gender- and culture-specific psychosocial and ecologic factors that influence HIV risk and protection for Mexican-American female adolescents [44]. SHERO demonstrates that collaborating with community organizations to implement HIV interventions and programs can assist in ensuring a high level of cultural congruence and a realistic potential of sustainability, if warranted [44]. Safer sexual behaviors and beliefs among Mexican-American female adolescents increased after participating in the 9-session SHERO intervention, compared with a single information-only HIV-prevention control session, demonstrating the value of tailoring an intervention to reflect cultural factors [44]. The quality of these community-based partnerships and the care taken by academic researchers to maintain them was essential for the recruitment and retention of adolescent participants and for the participation of additional community-based organizations to widen the reach of the program [42, 44, 45]. It is

important to note that each community and community-based organization is unique, so interventions and programs that involve partnerships among academic researchers, clinicians, and other providers are more likely to be successful [43]. For instance, a diverse coalition that worked to implement Project Bold, Ready, Intelligent, Dedicated, Guided, & Equipped (Project BRIDGE) generated initial ideas to develop a meaningful and context-appropriate HIV curriculum with experiential activities tailored to African–American/black middle-school students attending evening church sessions . The combined skills and active participation of the partners enhanced the likelihood that the HIV–prevention materials were meaningful and appropriate for, and thus respectful of, the unique culture and values of community members and the missions of partner organizations [40, 42, 43]. Further, the success of Project BRIDGE led to program growth and sustainability, with plans for continued collaborative activities and possible expansion to other churches and to schools. Part of the program’s success may be attributed to its original goals, which sought to harness religious affiliation as a protective benefit, while also reducing risk behaviors related to adolescence. Moreover, the faith community’s values and concerns were aligned and congruent with those of the academic researchers for the common goal of reducing HIV exposure and transmission [42].

The engagement and participation of adolescents in programs can be facilitated by organizational staff (e.g., youth pastors and outreach workers), whose intimate involvement in the study design can convey confidence and trust in the process to adolescents and parents [42, 43]. For example, the high level of engagement among adolescents in Project BRIDGE was attributed to the active involvement of organizational partners in the design and implementation of the program and to the building on existing strengths and resources of community partners [40, 43].

The YOUR Blessed Health intervention provides another example of the capacity of faith leaders and faith-based organizations to mobilize around prevention of HIV and other sexually transmitted infections (STIs) among adolescents in predominately African–American/black communities. The YOUR Blessed Health intervention was developed in collaboration among the Faith Access to Community Economic Development, Flint Odyssey House Health Awareness Center, Pastors’ Spouses of Genesee County, the University of Michigan School of Public Health, and the YOUR Center. After careful networking and trust building and ongoing relationship maintenance, this partnership developed a multilevel HIV- and STI-prevention intervention that respected church doctrine and built on faith-based institutional capacity to effectively promote HIV prevention . To date, more than 350 faith leaders from 55 churches across nine different dominations have trained over 15,000 congregants. Faith leaders’ involvement in the YOUR Blessed Health program enhanced the credibility of the intervention and the participating faith-based organizations’ capacity to address HIV with their congregants and in their communities [40, 46], and resulted in sustainability, further uptake, and broad reach of the intervention. The increased trust as a result of this intervention helped to increase HIV/AIDS awareness and reduce HIV-related stigma among the African–American/black faith community and among vulnerable adolescents.

Summary

A partnership approach to the development and implementation of each of these interventions and programs has helped to cultivate trust among academic researchers; representatives from

community and youth-serving organizations, health departments, clinics, and adolescents . Without a doubt, trust is necessary for the engagement and participation of adolescents in, and the success of, HIV prevention interventions [43]. The partnerships highlighted established trust among the partners. The high level of collaboration inherent in community-engaged prevention allowed each partner, including adolescents, to contribute to all phases of planning and implementation processes. Issues such as cultural congruence can be addressed as needed, thereby creating and ensuring a common foundation of understanding in each phase of the project [41, 42]. The highlighted interventions and programs underscore the value of culturally grounded HIV primary prevention services that are created in collaboration with adolescents and other partners to address ecologic factors affecting adolescents' HIV-related risk.

Identifying HIV-Positive Adolescents

Overview

The middle section of the integrated model focuses on testing and counseling services for adolescents . These services are essential to identify adolescents with HIV and prevent secondary infections. Furthermore, efforts to reach higher risk adolescents are important, as comorbidities (e.g., substance use and abuse and mental health issues) and frequent double stigma (i.e., race and sexual orientation) faced by adolescents may make it more challenging for them to seek testing services. These efforts help promote HIV testing by increasing accessibility and also by changing attitudes and beliefs to “normalize” testing [47, 48]. The hidden nature of higher risk adolescents has challenged academic researchers, clinicians, and other providers to develop and implement interventions and programs that have a community presence and can overcome the reluctance of adolescents to get tested and subsequently treated [34, 35]. Several interventions and programs have focused on innovative efforts to reach adolescents and increase HIV counseling and testing, including peer outreach workers to overcome barriers (e.g., insurance accessibility and mistrust of health-care professionals), mobile testing units, and venue-based testing programs (e.g., bars and clubs; [47]). In this section, we describe some of these types of intervention and programs; however, we do not describe venue-based testing programs, as they tend to be ubiquitous.

Youth-engaged Partnerships

Programs engaging adolescents have utilized a variety of strategies to increase HIV counseling and testing, including peer outreach workers from local communities and mobile testing units . The Teen Outreach Project University of Miami (TOP-UM), the Adolescent HIV/AIDS Project at the New Jersey Medical School, and the Chicago HIV Risk Reduction Partnership for Youth (CHRRPY) all used peer outreach to expand HIV testing services to higher risk adolescents [34, 39, 49]. Adolescents with HIV were involved as peer outreach workers who partnered with testing program staff to conduct pretest counseling, distribute educational materials, and facilitate follow-up appointments with higher risk adolescents [34, 39]. The incorporation of peer outreach workers in these programs helped overcome adolescents' mistrust of traditional health-care professionals and reluctance to approach clinics. Using peer outreach workers also increased the acceptability of HIV testing and counseling [34, 39, 49]. The results from these programs suggest that peer partners recruited from the community and representative

of the diversity of affected adolescent subgroups are able to best reach and engage other adolescents. For instance, peer partners from particular subgroups and/or subcultures were familiar with where adolescents congregated. Thus, they operated comfortably and easily within these settings [39]. Furthermore, they were more familiar with the way language was used and with the subtleties of language, which facilitated communication with adolescents, and, as a result, HIV testing [39].

In conjunction with peer outreach workers, mobile testing units staffed by peer educators, social workers, and counselors delivered HIV testing as a way to connect with adolescents who were resistant and/or reluctant to access and utilize traditional testing services [34, 49]. The mobile unit traveled to community settings where adolescents congregated “on-the-street,” thus serving to increase accessibility of testing services and reduce transportation barriers by going to adolescents rather than having adolescents come to them [49]. Inside the mobile units, adolescents received confidential screening for HIV infection, STIs, and mental health issues; were given appropriate referrals; and were offered prevention materials and risk-reduction counseling [49]. In addition, the mobile units provided HIV medical care and support services, such as case management, counseling, and peer advocacy [34] to ensure that adolescents who tested positive returned for posttest counseling and linkage to HIV treatment [49].

Organization-engaged Partnerships

Academic researchers, clinicians, and other providers have also often developed partnerships with youth-serving organizations to help identify HIV-positive adolescents in different settings and transition them into care [39]. Some HIV-counseling and -testing programs have partnered with agencies providing services to homeless adolescents, gay youth, youth detainees, and gang members [34]. For instance, staff from CHRRPY partnered with a large variety of youth-serving organizations to link clinical and program services. This partnership increased the number of adolescents receiving HIV counseling and testing, reduced adolescent risk behaviors, and, among adolescents who tested HIV-positive, increased the number that entered into comprehensive health-care clinics for early intervention and care [34, 39].

The Boston HIV Adolescent Provider and Peer Education Network for Services Program partnered with a network of youth-serving organizations, including multiservice outreach agencies, community health centers, and hospitals, to reach adolescents who were HIV-positive, homeless, and/or considered by community outsiders as hard-to-reach [50]. This collaboration served to provide a coordinated network of care for adolescents unable to access consistent care. The Division of Adolescent Medicine at Children’s Hospital Boston was the lead agency and primary site of HIV clinical care [50], and collaborative organizations covered a wide gamut of services, including case management, case coordination across sites, adolescent and HIV clinical care, and HIV education and training.

Social media/marketing campaigns have also formed partnerships with advertising and health communications agencies, adolescents, health-care providers, academic researchers, community-based organizations (e.g., Boys and Girls Club), and community advisory boards to promote HIV testing through adolescent-focused efforts [47, 51, 52]. These types of innovative partnerships can maximize the reach of the campaign and enhance its relevance to adolescents—both

important aspects in connecting with difficult-to-reach adolescents. Particular methods that can be used in forming effective messages to reach adolescent population subgroups include identifying competing narratives [51] that support healthy sexual behaviors while rejecting perceived norms of risk behaviors, consulting adolescents themselves to ensure their opinions are included in the development of intervention and program materials [47, 51, 52], and using culturally congruent messages to enhance protective health beliefs and behaviors [51, 52]. For instance, HIV-prevention campaigns with messages targeted to African–American/black adolescents presented messages that reflected African–American/black oral culture (e.g., skilled and expressive speech; [51]), included African–American/black adolescent actors [52], and partnered with advertising agencies that had experience in reaching this population [51].

By using social marketing to promote HIV testing through adolescent-focused efforts, such campaigns can normalize and reduce the stigma of HIV testing among adolescents and thus change their attitudes about such testing, while at the same time promote more routine testing among health providers [47, 53]. The relevance and quality of partnerships involved in these campaigns is a vital component to success in promoting the visibility of HIV infection and testing among adolescents, thus, increasing the number of higher risk adolescents participating in HIV counseling and testing.

Summary

Partnerships among academic researchers; representatives from educational and testing organizations, health departments, clinics, and other community-based organizations; and adolescents themselves can help to locate adolescents considered by community outsiders as hidden and hard-to-reach and to increase uptake of HIV counseling and testing. Adolescents in particular may be more comfortable and more likely to receive HIV testing in community-based (e.g., mobile testing units) rather than clinic-based venues, in part because of relatively low rates of adolescents seeking routine health care and low rates of providers and other staff offering testing to adolescents in clinical settings [54]. However, rates of successful linkage to care are lower in community-based settings compared with clinic-based settings [55]. Thus, better linkage to care in these venues is clearly needed to overcome adolescents' potential difficulty navigating fragmented care systems [e.g., separate testing and care sites; [56]).

Linking, Engaging, and Retaining HIV-Positive Adolescents in Care

Overview

The final phase of the integrated model is care services, which includes linkage to, and engagement and retention in, care for adolescents with HIV. Care services for secondary prevention refer to a systematic process of initiation of, and maintenance in, medical, psychologic, and social services. Care linkage refers to the systematic process of initiating HIV-related medical, psychologic, and social services for persons with newly diagnosed HIV [57]. Linkages that result in sustained engagement improve health outcomes among those with HIV and are important for community-level reduction in HIV exposure and transmission [58, 59, 60]. It remains a challenge for many providers to establish adolescents with HIV in care in a way that will preserve their health and prevent further disease transmission [10, 47]. Linkage to care is

particularly relevant for adolescents with HIV, who encounter more obstacles and challenges compared with adults (e.g., insurance, disclosure, and transportation; [61]) and are living with an often asymptomatic chronic illness [49].

Not being linked to and engaged in care is associated with delayed initiation of medication and poorer long-term clinical outcomes [59, 61]. Younger adolescents with HIV, in particular, have more difficulty establishing linkages with, and being retained in, care [61], which increases their risk of morbidity and mortality [62, 63]. Indeed, younger age is associated with worse retention to care in the first 2 years following an HIV diagnosis [60], and those with HIV who are younger than 35 years have more difficulty establishing, and being retained in, care [61]. This difficulty may be due in part to the relatively few HIV-related health services specifically designed for adolescents. Interventions and programs that aim to identify, engage, and retain adolescents with HIV ideally offer, or arrange for, medical care, case management, psychosocial support, and secondary prevention counseling [64].

Living with a chronic illness, adolescents with HIV face a lifetime of clinical care as they transition into adulthood. Routine health maintenance, ART adherence, and care retention across the life course are paramount as adolescents move through the integrated model [2, 65]. Tailoring services to their unique needs can serve to keep them engaged and retained in routine care [64] including during the transition from adolescent to adult care. This is a crucial period that hinges on the availability and accessibility of clinics specialized to address and welcome transitioning adolescents who may be hesitant to move from a youth-tailored clinic [15, 48].

Youth-engaged Partnerships

Several interventions and programs have worked to address the barriers to linking and keeping adolescents in care through youth-engaged research and programming to create a seamless transition from diagnosis to care [66, 67].

The peer-run organization known as Bay Area Young Positives (BAY Positives) was designed to decrease isolation, reduce risk behaviors, and promote advocacy skills among adolescents with HIV. Among its services, the program provides care linkage through its peer-based support and mentorship model [68, 69]. The organization has found that when young people are brought together to support each other, living with HIV becomes more manageable. The program also serves as a link to the clinical care system, empowering infected young people to gain information about and access to available services [68].

The Mobile SafeSpace program in New York City also used a peer education model to enhance program acceptability and help transition adolescents into care [49]. A fully equipped motor home served as an outreach unit and provided a comprehensive continuum of supportive services for street youth, including HIV testing, transport to safe and secure shelter, and connection to other necessary services. The program connected youth into care by traveling twice per day to areas where street youth congregated so that they could access these services [49].

Similarly, some of the Adolescent Medical Trials Network (ATN) clinics have used peer advocates (other adolescents with HIV) in its clinics. When they meet with peer advocates,

adolescents with newly diagnosed HIV are able to see someone living successfully with HIV and can ask questions that they may not feel comfortable discussing with their providers. These advocates help improve the relationships between adolescents with newly diagnosed HIV and clinic staff.

Community-based organizations have also more recently begun establishing HIV-specific youth advisory boards or committees in which adolescents are partners in program development and implementation. For instance, youth advisory boards at ATN clinics inform clinical policy (e.g., appointment protocols) and programs (e.g., “open mic night”) [24]. The adolescents provide insights into their needs and priorities and offer suggestions to make the clinic a place that is welcoming to adolescents with HIV. In addition, at several ATN sites, staff (e.g., child life specialists) collaborate directly with the youth advisory boards and other adolescents to develop and obtain resources for adolescent-specific programs designed to enhance adolescent engagement with the clinic [24].

Adolescent involvement in interventions and programs aimed at linkage, engagement, and retention in care is essential given that adolescents with newly diagnosed HIV face barriers at clinics because of their potential lack of experience with the health-care system. Adolescents with HIV may be more likely to engage in care services if they have support from other adolescents, who may reduce their perceived fear and distrust of clinics, while also providing social support [49, 68].

Organization-engaged Partnerships

In conjunction with direct youth engagement, academic researchers, clinicians, and other providers partner with youth-serving organizations to support care linkage and engagement. One ATN program, the Strategic, Multisite Initiative for the Identification, Linkage and Engagement in Care of Youth with Undiagnosed HIV Infection (the Care Initiative), was designed to facilitate care linkages and engagement processes for adolescents with newly diagnosed HIV through formal partnerships between the ATN clinical sites, local health departments, and community-based organizations. A memorandum of understanding between partners was developed to describe linkage-to-care processes, specify public health authority (if any) granted to the program, and specify sharing (if any) of patient-related data. These partnerships allowed for a more streamlined process from diagnosis to care across testing and treatment networks [15]. The program also assisted with care engagement through relationship development between adolescents and staff and increased connections of adolescents to clinics [24].

Another ATN-specific strategy is the development of community coalitions through Connect2Protect [70]. The Connect2Protect coalitions are designed to address structural issues related to HIV-prevention strategies, including facilitating adolescents’ engagement in HIV-related services [70].

After an adolescent is linked to care, the primary goals become supporting this adolescent’s retention in care and medication adherence, once prescribed. These activities typically occur within the clinic, limiting the utilization of partnership models. One useful strategy for maintaining adolescents in care is active case management and the provision of integrated,

comprehensive services [37, 71]. The Division of Adolescent Medicine at Children’s Hospital Los Angeles implemented an integrated care model for adolescents with HIV that included HIV care plus psychosocial services such as case management, counseling, and related ancillary services [71]. A key aim of this project was to ensure the privacy and confidentiality of HIV status for adolescents in the waiting room to decrease passive disclosure and increase comfort with and confidence in the clinic [71]. Other work has addressed the role of adolescent-friendly clinics in facilitating engagement in HIV care among adolescents [24]. Through these adolescent-focused efforts, adolescents with HIV may be more likely to remain in care because of increased trust of health-care professionals and acceptability of care settings and services [24].

After being engaged in care and prescribed medical therapies, HIV medication adherence becomes of utmost importance for adolescents, especially within the treatment as prevention model [12, 92]. Research illustrates that adolescents’ perceptions of, and experiences with, ART is largely negative, indicating that adolescents may need support for managing their care and treatment regimens [72]. Accordingly, adolescents have low rates of reported adherence [76] and of achievement and maintenance of undetectable viral loads [77]. There is interest in improving adolescent adherence to medication regimens through the use of directly observed therapy [73], support group networks [74], and social media (e.g., Facebook and MSM networking sites [75]). Although existing research has supported the feasibility of a modified directly observed therapy among adults in particular, few studies have determined feasibility with adolescents. Community-based modified directly observed therapy programs tailored to the unique needs of adolescents with HIV can improve adherence to medication regimens and provide psychosocial, public health, and other medical benefits, particularly social and emotional support gained from relationships with program staff [72, 73] or peers [74]. For example, to promote adolescent adherence to ART, the Therapeutic Regimens Enhancing Adherence in Teens (TREAT) Program used adolescents’ perspectives to develop and implement an evidence-based clinical intervention to promote optimal, long-term adherence to medication among adolescents with HIV [76].

Increasing adolescents’ comfort with care-seeking behaviors can also be enhanced through the connection to “place” (e.g., clinic and community-based organization) and/or “people” (e.g., peer educators and program staff), in addition to the provision of appropriate and needed services. Adolescents with HIV, particularly those who are difficult to engage in care, have a unique set of needs and motivations affecting their care behaviors. These potential issues may be alleviated as comfort increases with the specific clinic space and/or as relationships develop with a peer or program staff [24, 35, 37, 49]. Connection to place and people who are trained in adolescent-specific issues and contexts can facilitate progression through the integrated model, especially at the crucial moments of care linkage and transition to adult care [24].

Summary

Overall, care linkage programs have benefited from partnerships across diagnostic and care networks (Fig. 1); engagement in care programs have relied more exclusively on clinic resources. Improvements in retention in care could be made through engaging adolescents and youth-serving organizations in the programming process.

Lessons Learned

Benefits and Challenges of Youth-Engaged Partnerships

The integrated model provides a variety of lessons related to HIV prevention and care among adolescents. Creating interventions and programs that address the specific needs, interests, and priorities of adolescents requires their engagement and participation. In partnering with adolescents, academic researchers and representatives from educational and testing organizations, health departments, clinics, and other community-based organizations, for example, should ensure that adolescents are engaged in effective and meaningful participation [32].

First and foremost, adolescents' knowledge and experience make them important partners in HIV-prevention research and programs. The value of including adolescents lies in the insights they can provide in understanding contextual issues, perceptions, and areas of need. These insights can help to enhance intervention relevance and sustainability [73, 78]. Many existing programs involve adolescents but do not engage them as full partners. Although it can be challenging to partner with adolescents, as they may have unpredictable schedules, conflicting views, and other responsibilities, efforts must focus on helping adolescents understand that they (and their input) are crucial for programming. Perhaps more important, however, program staff must be flexible and patient to make partnership possible for adolescents and also be open to the differing perspectives and insights provided. A high level of creativity is often needed, and program staff often assume that they know the answers or have the insights based on their ongoing service provision. However, HIV-prevention interventions and programs may particularly benefit from partnerships with local adolescents, as these adolescents (in comparison to program staff) may be able to better identify, and reach out to, marginalized and higher risk adolescents to educate, get tested, and facilitate care linkage if positive.

Adolescent partners partnering can provide vital input on intervention and program components, such as whom to employ as study recruiters and facilitators, intervention strategies and format, relevant content and delivery options, acceptable recruitment and intervention locations, and incentive structures. For instance, the researchers involved with Choosing Life: Empowerment! Action! Results! (CLEAR), a client-centered intervention, improved on their previous iteration by better tailoring to the concerns and life situations of adolescents: providing one-on-one counseling sessions rather than small groups to protect HIV disclosure, providing telephone sessions to increase accessibility, and updating the delivery modalities to make them specific to each adolescent's unique situational context [79].

Furthermore, adolescents can contextualize the barriers and context of adolescents' behavioral decisions [2, 13]. Thus, a wide range of adolescents—not just adolescents who are popular community leaders, more proactive, and/or easier to reach and work with—should be engaged, and have an opportunity to adapt their level of participation to their changing developmental needs. Adolescent participation should also take place in the context of a realistic time frame that can foster the development of new skills. Adolescents can be engaged on short-term projects that they can successfully finish, although some adolescents may be willing and available for full project engagement from start to completion.

Adolescents should be given increasingly complex responsibilities that match both the needs of the intervention and/or program and the adolescents' stage of development. Adolescents benefit through engagement and participation and increased roles and responsibilities (e.g., increased research skills and helping others); however, their work needs to be supported with appropriate human, financial, and logistical resources. It is important to note that adolescents must be informed about the rights and responsibilities involved in human subjects research; human subjects training can contribute substantially to ensuring that confidentiality concerns are addressed in an effective, context-specific manner [32] and at the same time develop adolescents' understanding of, and ongoing contribution to, research. Adolescents should also receive incentives to encourage their participation. Compensation for adolescents' involvement in research aids in shared power in the research process [80], while ensuring the ethical engagement of adolescents as partners [81].

The population of adolescents at risk for, and infected with, HIV is not a homogenous group. Academic researchers, clinicians, and other providers must pay attention to similarities and differences (e.g., gender, sexual orientation, race/ethnicity, and geography), as these factors affect the ways in which adolescents conceptualize their risk for HIV exposure and transmission and also affect the availability and accessibility of services. Although HIV disproportionately affects young sexual minority adolescents (e.g., gay and bisexual), especially young African-American/black and Latino/Hispanic gay and bisexual men, MSM, and transgender persons, other sexual orientations, races, and ethnicities must also be included in prevention research [9]. Female adolescents, including lesbians and other women who have sex with women (WSW), may be marginalized or ignored, given that many programs are specific to MSM [82]. Furthermore, racial/ethnic minority female adolescents may have specific individual and dyadic needs shaped by cultural values and beliefs that affect HIV-prevention and -care efforts. Contextual issues that are specific to women, such as violence and gendered power dynamics in heterosexual relationships, must also be considered [83]. Thus, partnering with adolescents representing diverse experiences and backgrounds can help interventions and programs meet the unique needs of adolescents with respect to demographics, context, culture, values, and beliefs [25, 34, 40, 49, 84].

Benefits and Challenges of Organization-Engaged Partnerships

As adolescents at risk for and with HIV are often considered by community outsiders as hidden or hard-to-reach, additional time and effort may be needed [34, 35], thus highlighting the utility of partnering with youth-serving organizations. Therefore, the importance of other community partners cannot be underestimated. For example, youth-serving and faith-based organizations can be involved in HIV-prevention efforts for adolescents. In line with community-based participatory research (CBPR), partnering with community-based organizations shows promise for academic researchers, clinicians, and other providers, in particular, to tap into the expertise and community-level knowledge of these organizations, allowing a "blending of lived experiences" [85]. Interventions and programs using community engagement to support adolescents with HIV have explored collaborations with youth-serving organizations to develop comprehensive culturally and ecologically tailored interventions and programs. Youth-serving organizations have played a unique role in prevention and health promotion efforts because of their position as frontline service providers. They offer an intimate and essential perspective to

the factors influencing HIV risk, exposure, and transmission within communities and insights for the development and implementation of culturally congruent HIV-prevention interventions and for formulation of partnerships with adolescents [86]. Additionally, engaging organizational partners aids in recruitment and retention of adolescent participants and additional organizational partners [43].

Forming community–academic partnerships when designing programs can be helpful in ensuring that adolescent perspectives are integrated into the process of intervention and program development [13]. Compared with academic researchers, clinicians, and other providers, youth-serving organizations are able to develop different relationships with adolescents that may or may not be related to HIV and serve in a different capacity to meet the needs of adolescents. As many youth-serving organizations focus on specific issues and populations (e.g., racial/ethnic minorities, sexual orientation, and geography [urban/rural]), these partnerships have been particularly useful for engaging adolescents epidemiologically at risk for HIV acquisition. Organizational partners’ roles can be expanded to include health education through activities that correspond with institutional beliefs, doctrines, and culture [41]. Engaging community partners, including nonhealth community institutions (e.g., community- and faith-based organizations) with existing relationships with adolescents, in HIV-prevention and -care efforts is helpful. Specifically, these partnerships can assist: in facilitating adolescents in accessing a diverse array of services, in coordinating care across agencies and institutions, in mobilizing communities around the issue, in enhancing community capacity, and in changing community norms to better integrate and fully consider the social-ecologic context of local adolescents [37, 45].

When collaborating with youth-serving organizations, it is important to develop and harness their capacity, strengths, and resources by accommodating each organization’s individuality and culture [40, 41, 42, 45, 85]. To ensure cultural congruence, ecologic factors should be addressed, such as community and cultural norms, community priorities, acculturation, familial norms/expectations, gender role expectations, and ethnic pride [42, 44, 85]. For example, to navigate the sensitivity of HIV discussions in faith-based settings, it may be helpful to ensure that the program is congruent with the values, beliefs, and comfort levels of adolescents, their parents, and faith leaders. It is also important to frame the program in a way that addresses members’ perceptions of HIV and frames HIV as a public health and medical issue rather than a sexual or moral issue [40, 41, 46, 87]. Although a certain level of stigma may exist for faith-based organizations (e.g., discomfort with being “out” at church due to homophobia or homonegativity), these faith-based partnerships can help diminish the stigma because of the trust that parents and local community members have for these institutions [40, 42].

Organizational partnerships serve to enhance community capacity and intervention sustainability and to foster mutual learning, understanding, and trust. Community coalitions can be especially useful in formalizing partnerships, attending to diverse perspectives, and promoting resource sharing and sustainability [70, 88]. As funding policies are beginning to require partnerships (e.g., HIV-testing programs must have linkage partners), a more collaborative approach is imperative. This approach is helpful; as has been noted, “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” [70].

Lastly, maintaining access and connection to services across the transition points within the integrated model is important to keep adolescents involved in research, interventions, and programs and is especially important for secondary prevention efforts. Integrating adolescents’ perspectives to enhance accessibility and acceptability of prevention and care services may help establish trust and comfort among adolescents. This, in turn, may help adolescents disclose to particular persons (e.g., staff and providers) and use particular places (e.g., organizations and clinics). Traditional client-provider relationships may not be sufficient for developing these trusting relationships. Instead, partnerships in which adolescents can be true partners may allow for a flexible and adjustable system of relationships and services [37, 84]. Programs can serve as a bridge or mediator between adolescents with HIV who are considered by community outsiders to be hidden or hard-to-reach and health-care delivery systems; a program’s presence can motivate adolescents to be tested or engaged in care through institutional referrals or word-of-mouth [34]. For counseling and testing efforts conducted within institutional settings, accessibility and acceptability may mean being as unobtrusive as possible and normalizing HIV testing as nonthreatening. Within community settings, this may mean establishing a distinct, consistent presence to build both individual and community acceptance. In all settings, risks to privacy and confidentiality must be considered to ensure acceptability and comfort with the program and to respect and protect adolescents [37, 73].

Research Needs and Priorities

Partnerships among academic researchers; representatives from educational and testing organizations, health departments, clinics, other community-based organizations, and adolescents are needed and should be established across the spectrum of the integrated model to create a seamless transition from HIV prevention, testing, and diagnosis to HIV-related care [15, 89, 90]. Thus, research should continue to use innovative strategies to develop and sustain direct partnerships with adolescents and consider the role that community-based youth-serving organizations can play in HIV prevention and care. Ongoing community collaborations to address structural level changes are useful in decreasing the incidence of HIV and keeping adolescents with HIV healthy [70, 88].

The implementation of enhanced testing initiatives has heightened the need for a more developed set of tools for HIV prevention and 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 provide education to improve retention in care. At the federal level, grantors, including the US Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), can play an important role in facilitating the collaboration among academic researchers; representatives from educational and testing organizations, health departments, clinics, other community-based organizations, and adolescents through grant requirements [24]. These approaches will be a vital foundation to effectively realizing goals outlined in the *National HIV/AIDS Strategy* [66, 67].

Studies show that strong partnerships and networks aid in structuring efficient HIV-prevention and -care models that avoid service duplication and promote the health of adolescents [15, 70]. The integrated model demonstrates that HIV prevention and care are lifelong issues, especially for adolescents with HIV. Thus, it is important not only to get adolescents engaged in the clinic but to acknowledge that adolescents must eventually transition to adult care and away from the clinics and providers that are safe and known to them [24].

Future research should explore adolescents' attrition along the HIV-care continuum (e.g., diagnosis to care and transitions from adolescent to adult care) through adolescent partner insights and ethnographic and qualitative research methodologies to obtain deeper understandings of the perspectives of adolescents with HIV. For intervention and program planning to be successful, it is essential to gain a better understanding of adolescents' views on HIV risk reduction behaviors (e.g., whose responsibility is it to use condoms and factors associated with retention and attrition in care), the motivations for these behaviors (e.g., altruism, fear of infecting others, and fear of legal reprisal), and other insights and underlying emotions.

Discussion and Conclusion

The ongoing HIV epidemic among adolescents in the USA highlights a profound and immediate need for innovative approaches to primary and secondary prevention that engage adolescents as equal partners [55, 91]. The *integrated model of continuities in transition in adolescent HIV prevention, diagnosis, and care* [16] provides a helpful framework to depict the variety and stages of community-engaged scholarship that have emerged and examples of partnerships with adolescents and youth-serving organizations. Although academic researchers, clinicians, and other providers have created interventions and programs that receive input from adolescents, adolescent partnerships are rarely utilized to the fullest extent possible. It is imperative that research programs partner with adolescents so they can improve the relevance of intervention and program planning, implementation, and evaluation. Engaging adolescents and youth-serving organizations in participatory research and practice requires listening to adolescents' voices and acting on their recommendations with the same rigor as adult voices in the reflection and decision-making process [32]. This process is essential for the development and implementation of culturally relevant HIV-prevention programs.

In this chapter, we demonstrated how engaging and partnering with adolescents and hearing their voices has multiple benefits, such as better recruitment of adolescents in HIV-prevention and -care interventions and programs, decreased fear and distrust of health services, reduced barriers to testing and care, and improved identification of needs and priorities. Although each of these benefits can be useful throughout the integrated model, particular benefits are salient in each of the integrated model's phases.

In addition, engaging adolescents in program planning can lead to the development of more appropriate materials and more culturally congruent interventions and programs overall [32]. This overall enhancement can be accomplished through stronger adolescent-tailored language in educational sessions and questionnaires, potentially increasing the strength and quality of the collected data [32]. Trusted community- (e.g., SHERO; [44]) and faith-based organizations (e.g., Project BRIDGE; [42, 43]) can be powerful partners in addressing HIV among adolescents,

reducing fear of involvement and/or increasing comfort in using prevention services, as well as improving overall community acceptance.

Interventions and programs promoting HIV testing and counseling may benefit from adolescent partners who aid in overcoming barriers to reach higher risk adolescents and positively influencing attitudes and beliefs related to testing. The involvement of peer workers in various aspects of program implementation has helped to increase acceptability of HIV testing and counseling among adolescents considered to be hard to reach as some of these adolescents have not otherwise been to a clinic [34, 39, 49]. Engaging adolescents can also help in the identification of better communication channels and optimal locations to reach adolescents, such as in the use of mobile testing units to deliver on-the-street testing, thereby increasing accessibility of services and reducing transportation barriers [49]. The particularly vulnerable nature of adolescents at higher risk for, or currently living with, HIV who may also be experiencing comorbidities makes it essential to include youth-serving organizations. Social marketing campaigns [47] and community-based, rather than clinic-based, settings for intervention or program delivery [54] can assuage the stigma and misconceptions among adolescents regarding using health-care services.

Lastly, interventions and programs related to care services have benefited from adolescent partnerships by identifying specific needs and priorities of particular subgroups. Such partnerships aid in the identification of important characteristics of key staff members, such as the need to hire peer educators with experience living on the streets for an intervention recruiting street youth [49]. Involving adolescents in programs related to care linkage, engagement, and retention can also build social support among adolescents and between adolescents and program staff [72, 73]. Indeed, adolescents with HIV may be more likely to stay in care if they receive support from peers. In successful programs such as BAY Positives [68], Mobile SafeSpace [49], and TREAT [76], positive intervention and program outcomes and sustainability would have been more difficult to achieve without the involvement of adolescents in the implementation process.

In summary, adolescents represent a unique population in terms of behavioral risk factors, cognitive and psychosocial development, and potential length of HIV disease trajectory. Thus, both primary and secondary HIV-prevention and -care efforts are essential. The ultimate goal of HIV prevention among adolescents is to keep them negative, or if they become positive, to keep them healthy as they navigate their disease status while maturing into adults. For adolescents who become positive, it is imperative to create programs that will help them overcome barriers to health-care access and increase their involvement in their own care. Including other adolescents and youth-serving organizations in the linkage-to-care process can help adolescents communicate with health-care providers and locate clinics that best meet their own needs. Working closely to keep adolescents engaged in care and adherent to medication will improve both individual and community/population health by reducing secondary transmission. As we further explore biomedical (e.g., vaccines, microbicides, and PrEP) and behavioral (e.g., test and treat and treatment as prevention) interventions and programs, partnering with adolescents and community-based youth-serving organizations to improve HIV prevention will only become more important in the future.

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