



Youth and Young Adults and the Ryan White HIV/AIDS Program

September 2015

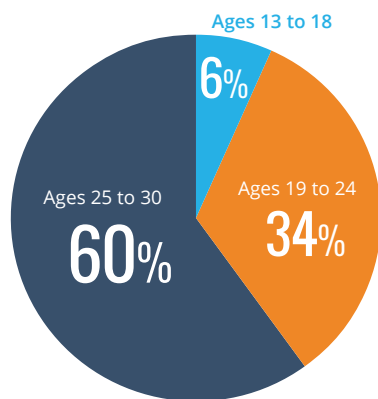


To address the burden of HIV among young people and prevent further transmission of the virus, it is critical to strategically target prevention messages and to increase engagement of young people in HIV medical care. Youth represent a medically underserved population in the United States,¹ and successfully connecting with and caring for this population requires tailored approaches. Of the approximately 525,000 clients served by the Ryan White HIV/AIDS Program during 2013,² 15% were youth and young adults (hereafter referred to as “youth”) aged 13–30 years (Figure 1). Consistent with national surveillance data and trends,³ these youth, particularly those aged 19–30 years, were most likely to be black men who have sex with men (BMSM). Among female youth clients, 86% were racial or ethnic minorities.²

This report outlines the Health Resources and Services Administration’s (HRSA) longstanding history serving youth, the health disparities that exist among this population, barriers youth face in engaging in care, data trends among Ryan White HIV/AIDS Program clients aged 13–30, and the ways in which grantees are overcoming challenges to successfully develop youth-centered programs.

Figure 1. Youth Served by the Ryan White HIV/AIDS Program, 2013

Ages 13–30, N=79,050



Source: Ryan White Services Report data, 2013

History of Youth-Focused Initiatives

The Ryan White HIV/AIDS Program has made a concerted effort throughout the years to focus attention on youth affected by HIV. In 1993, the Pediatric AIDS Service Demonstration Grants, administered by the HRSA for HIV-positive children and their families, were incorporated into the Ryan White HIV/AIDS Program, specifically the Part D program for women, infants, children, youth, and their families. Also beginning in 1993, the Special Projects of National Significance (SPNS) program funded 10 models of adolescent HIV care through the Adolescent Care Demonstration and Evaluation Initiative.⁴ This multiyear project evaluated four categories of interventions:

- ▶ youth involvement
- ▶ outreach to bring youth into services
- ▶ case management and linkage to services
- ▶ a comprehensive continuum of care

Did You Know?

National statistics on youth and HIV

- ▶ According to national HIV incidence surveillance data from 2007 to 2010, individuals aged 13 to 24 accounted for 26% of new HIV infections.
- ▶ In 2012, nearly 45% of youth with HIV in the United States were unaware of their infection.

Sources:

CDC. *Estimated HIV incidence in the United States, 2007–2010. HIV Surveillance Supplemental Report 2012;17(No. 4).*

<http://www.cdc.gov/hiv/library/reports/surveillance/>

CDC. *Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2013. HIV Surveillance Supplemental Report 2015;20(No. 2).*

<http://www.cdc.gov/hiv/library/reports/surveillance/>

SPNS has also funded engagement and retention in care initiatives for high-risk youth populations. Specifically, the Outreach, Care, & Prevention to Engage HIV Seropositive Young Men who have Sex with Men (MSM) of Color Initiative focused on developing and evaluating innovative service models targeting HIV-infected men who have sex with men aged 13–24.⁵ Other recent HRSA initiatives targeting young MSM (YMSM) include:

- ▶ UCare4Life: a mobile texting program that helps patients with HIV infection better adhere to medication regimens
- ▶ The Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men: a cooperative agreement that seeks to identify and disseminate best practices and models, particularly for BMSM aged 13–24.

HRSA publications focusing on youth in addition to this report include: newsletters focusing on the delivery of culturally competent care to young adult patients and transitioning adolescents from pediatric to adult care settings; and a population fact sheet on HIV and youth, detailing the critical issues faced by this population and featuring highlights of the Ryan White HIV/AIDS Program's response.

HRSA Data:

Where do they come from and how are they used?

The Ryan White HIV/AIDS Program Services Report (RSR) is the HRSA HIV/AIDS Bureau's (HAB) primary source of annual, client-level data collected from its nearly 2,000 funded grantees and providers.

These data are used to assess the number and type of non-AIDS Drug Assistance Program clients receiving services, as well as the quality of HIV care. Client-level RSR data collection has been in effect since 2010. Agencies that provide any Ryan White HIV/AIDS Program clinical or supportive services are required to submit data to HAB each year in a specified format. Those data contain an encrypted, unique identifier for each client and, depending on the type of agency reporting, additional demographic, service, and clinical data. Demographic data include the client's gender, race/ethnicity, health care coverage, poverty level, and housing status. Service data include the number and date of outpatient ambulatory medical care visits as well as visit counts for other core medical services, including mental health, substance abuse, and oral health. Providers of outpatient ambulatory medical care also report all viral load and CD4 test results and dates, as well as information concerning receipt of screening tests for hepatitis B, hepatitis C, and syphilis.

This array of data enables HAB to calculate important measures of performance, including viral load suppression and retention in HIV care—two central components of the National HIV/AIDS Strategy.

Health Disparities among Youth

Stigma and disclosure are two barriers to HIV care for clients, regardless of age. These issues, however, may be particularly acute among youth because adolescence and young adulthood are marked with self-identity exploration and sexual awakening.⁶⁻⁸

Adolescence is a psychologically complex time characterized by lowered inhibitions, increased risk-taking behavior, and decreased parental support and oversight.⁹ Meanwhile, the establishment of romantic relationships, feelings of invulnerability, and choices regarding drug and alcohol use are distinct characteristics of this period.⁹

The U.S. Centers for Disease Control and Prevention (CDC) Youth Risk Behavior Survey found that 47% of high school students were sexually active and only 59% used a condom during their last sexual encounter. Of sexually active students, only 13% had been tested for HIV.¹⁰ These factors, individually and in combination, place youth at increased risk for sexually transmitted infections (STIs), including HIV.

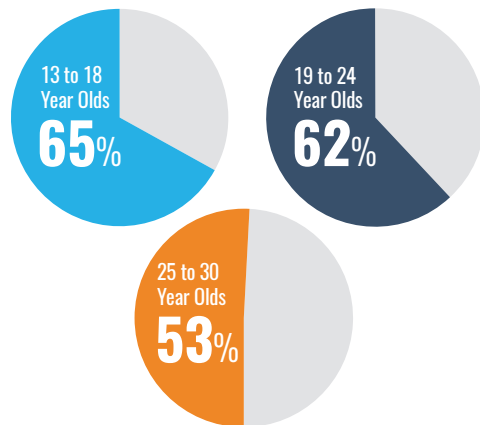
Fear of violence, rejection, discrimination, and confidentiality related to HIV status and sexual orientation are among the leading causes of delayed initiation into care and treatment by youth.⁶⁻⁸ Compounding these factors are the structural challenges youth face when accessing and navigating the health care and insurance landscapes, regardless of whether they were perinatally or behaviorally infected. These barriers range from cost for care or co-pays, lack of transportation, low health literacy, competing priorities, and limited educational attainment.⁶ In fact, among Ryan White HIV/AIDS Program clients, only 40% of youth aged 13–18 utilized outpatient/ambulatory medical care during 2013, compared to 56–63% among clients in other age groups.²

Disparities among Racial/Ethnic Minority Youth

HIV infection is inextricably linked to a host of health, social, and structural issues that are more pronounced within communities of color. These include poverty, psychological comorbidities, substance use, sexual victimization, stigmatization, and discrimination, all of which undermine the health and well-being of infected persons, including youth. Vulnerabilities such as these are cumulative and support the notion of a *syndemic*, or set of mutually reinforcing epidemics driven by cultural marginalization, that heightens the risk for acquiring HIV.¹¹⁻¹⁴ In the United States, communities of color, particularly black, non-Hispanic communities of color, are most severely affected by HIV infection; the highest rate of new infections is among young, black, non-Hispanics,¹⁵ which underscores a need to strategically reach a new generation of people.

Figure 2. Black, Non-Hispanic Youth Served by the Ryan White HIV/AIDS Program

by Age Group, 2013



Source: Ryan White Services Report data, 2013

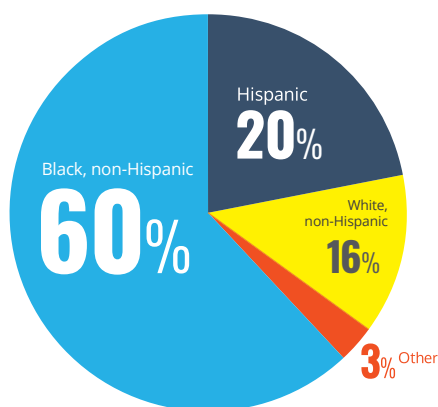
Consistent with the burden of HIV among youth in the United States, black, non-Hispanic youth represent the largest racial/ethnic group among Ryan White HIV/AIDS Program clients aged 13–30. As Figure 2 illustrates, black, non-Hispanics represent the majority of young clients served by the Ryan White HIV/AIDS Program across all age cohorts of young people.

Young Women

Young women of color are also disproportionately affected by HIV and are well represented in the Ryan White HIV/AIDS Program: during 2013, approximately 86% of female Ryan White HIV/AIDS Program clients aged 13–30 were women of color.

Figure 3. Young Women of Color Served by the Ryan White HIV/AIDS Program

Ages 13–30, by Race/Ethnicity, 2013



Source: Ryan White Services Report data, 2013

Heterosexual contact was the leading cause of transmission among young women and accounted for 26% of all infections among Ryan White HIV/AIDS Program clients aged 13–30. Figure 3 illustrates the distribution by race and ethnicity of young women aged 13–30 who received Ryan White HIV/AIDS Program services during 2013.

Young women have several risk factors for HIV infection. Male-to-female transmission of HIV is approximately 2 to 4 times more efficient than female-to-male transmission, due to the permeable mucous membranes of female reproductive organs.¹⁶ In addition to anatomical risk factors, beliefs about gender roles, knowledge of sex and sexuality, and gender inequality in relationships all play important roles in determining girls' risk factors and risk behavior.^{17–19} Trauma and intimate partner violence (IPV), as well as associated post-traumatic stress disorder (PTSD), are also significantly higher among HIV-positive women and girls, than among the general population of women. Risk associated with IPV and HIV is two-sided: Women and girls are at increased risk for violence because of their HIV status, and those who experience violence are at increased risk for being infected with HIV.^{20,21} Among women and girls who have experienced IPV in the United States, 69% experienced this violence at age 25 or younger, and 22% experienced IPV for the first time between the ages of 11 and 17 years old.²²

Trauma and IPV are linked to poorer health outcomes along the HIV Care Continuum.²¹ For many women and girls, engagement in care and medication adherence cannot be separated from painful reminders of violence or betrayal. As "Tammy," a Ryan White HIV/AIDS Program Part D client, says, "I know I need to take my meds. It's just so hard some days. I thought we were in love. I thought he was monogamous. Now, every day from here until forever I have to live with a reminder of what he's done. I can never escape it."

Young MSM

Gay, bisexual, and other men who have sex with men have particularly high rates of HIV infection and face their own unique set of challenges. For example, social networking sites for sex-seeking are particularly popular among YMSM and contribute to an increased number of sex partners and increased risk for STIs.²³ As one Ryan White HIV/AIDS Program YMSM client states, "It's easier to find a hook-up online now than it is to order Chinese takeout." He adds, "It's the reverse order of a relationship. We hook up first and then if there is chemistry and real connection, then maybe you'll date. Quite honestly, we only see heterosexual relationships in the media. I don't know what a healthy, black, gay relationship looks like. I've never seen it."

Among Ryan White HIV/AIDS Program clients aged 13–30, MSM was the transmission category for 60% of infections. The racial/ethnic distribution among YMSM in 2013 was 54% black, non-Hispanic; 22% Hispanic; 20% white, non-Hispanic; and 4% other races.

Black, non-Hispanics were particularly overrepresented among YMSM aged 13–24.* This is consistent with national trends: from 2009 to 2013, young, black MSM aged 13–24 had the largest increase in diagnoses of HIV infection compared to other racial/ethnic groups of YMSM—from 3,895 diagnoses in 2009 to 4,643 diagnoses in 2013.²⁴

MSM of color, including YMSM of color, tend to select sexual partners who are of the same race/ethnicity. Higher HIV prevalence, coupled with a smaller dating community, place these individuals at increased risk.^{25–27} MSM, especially YMSM, may also underestimate their risk or make inaccurate assumptions about their partner’s HIV status. For example, the National HIV Behavioral Surveillance System conducted HIV testing in 20 cities and found that only 49% of HIV-positive YMSM aged 18–24 knew of their infection.²⁸ For black YMSM, partnering with older black men (among whom HIV prevalence is high) may also lead to increased risk, particularly as HIV prevalence is found to increase with age among the MSM population.²⁷

*Among RSR clients, approximately 68% of YMSM aged 13–18 were black, non-Hispanic, and 62% of YMSM aged 19–24 were black, non-Hispanic

Transitioning into Adulthood: Behaviorally Infected Youth and Perinatally Infected Youth

The efficacy of HIV antiretroviral therapy (ART) has greatly improved life expectancy for HIV-positive individuals and, as a result, many adolescents are making the transition into adult care systems. By the age of 21, HIV-positive young adults should make a planned, purposeful switch from child-centered to adult care.²⁹ The differences between these care models are well-documented, and the primary difference is fragmentation of services. While child-centered care facilities utilize multidisciplinary teams of pediatricians, nurses, social workers, psychologists, child life therapists, and other dedicated caregivers, adult-oriented care often fails to include both medical and psychosocial services.²⁹ These services are especially important as HIV-infected young people have higher rates of mental health issues like anxiety, depression, and PTSD than their HIV-negative peers.⁷

Perinatally infected youth account for 9% of Ryan White HIV/AIDS Program clients aged 13–30, compared to 87% of behaviorally infected youth, and 4% other transmission modes. Perinatally infected youth often experience drug resistance after many years of ART therapy and, in some cases, inconsistent treatment adherence. Because of this, they are more likely to have complex,

intolerable medication regimens and to be in advanced stages of HIV disease compared to behaviorally infected youth.³⁰ The most common barriers to care experienced by both groups are forgetting to take medication and consciously deciding to take a break. A higher number of identified barriers is also associated with poorer medication adherence.³¹

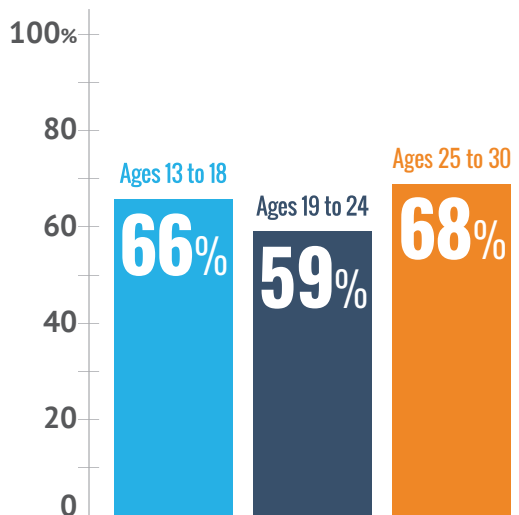
Many youth, particularly those perinatally infected, establish strong emotional attachments to their pediatric health care providers and are reluctant to break these bonds. Consequently, transitions can be very challenging, and 50% of perinatally infected youth report adherence difficulties post-transition.³² As “Luisa,” a perinatally infected Ryan White HIV/AIDS Program client explains of the transition, “I’m not scared of leaving [pediatric care], and I know I can come back and visit. But it’ll be different. I can’t open up to everybody and have them walk out of my life,” she says. “I’ve had that my whole life going in and out of foster homes. I’ve finally found people I trust and I don’t want to start over.”

While Luisa’s story is unique, her concerns are not. Creating a supportive environment for youth transitioning to adult care requires understanding the circumstances surrounding where these clients are coming from and who they are. The vast majority of Ryan White HIV/AIDS Program clients are racial and ethnic minorities, and almost all are dealing with the effects of poverty and lack of private insurance. For most of these clients, life has been filled with uncertainty and has been anything but easy. Many youth received little or no medical care or access to information about their health prior to becoming HIV-positive and entering care at a Ryan White HIV/AIDS Program-funded facility. For youth facing developmental, security-related, and mental and physical health-related challenges, these challenges do not necessarily disappear when clients enter adult care and, thus, providers need to create a welcoming environment where youth feel safe and supported.

Viral Suppression and Retention in Care

Knowledge of HIV infection, retention in HIV care, and viral suppression are key pieces of the HIV Care Continuum and carry both individual and public health benefits.³³ Having access to caring and culturally competent staff within a welcoming environment can mean the difference between youth engaging in services and moving along the HIV Care Continuum or walking out the door. “Why would I go across town to have a receptionist give me attitude and then sit in some cold, sterile waiting room for 30 minutes just to be seen for 10?” asks “DaShawn,” a Ryan White HIV/AIDS Program youth client. “It’s got to be a place I’d want to hang out. Even better if the people working there look like me.”

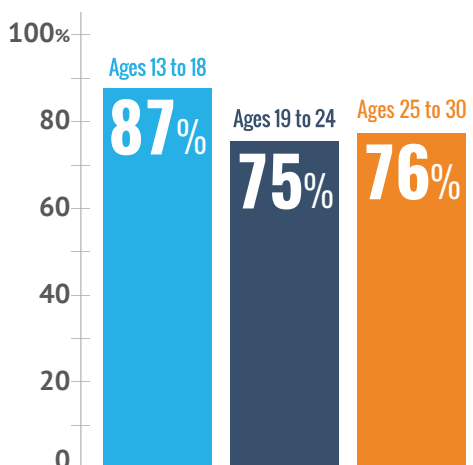
Figure 4. Viral Suppression among Youth Served by the Ryan White HIV/AIDS Program by Age Group, 2013



Source: Ryan White Services Report data, 2013

Ryan White HIV/AIDS Program grantees and providers have found ways to successfully connect with youth, and better viral suppression outcomes have been seen among youth in Ryan White HIV/AIDS Program settings compared to national estimates.³⁴ But there is room for improvement: for example, among Ryan White HIV/AIDS Program clients of all ages, approximately 79% were virally suppressed in 2013; youth clients, however, had lower percentages of viral suppression than the average, as illustrated in Figure 4.

Figure 5. Retention in HIV Care among Youth Served by the Ryan White HIV/AIDS Program by Age Group, 2013

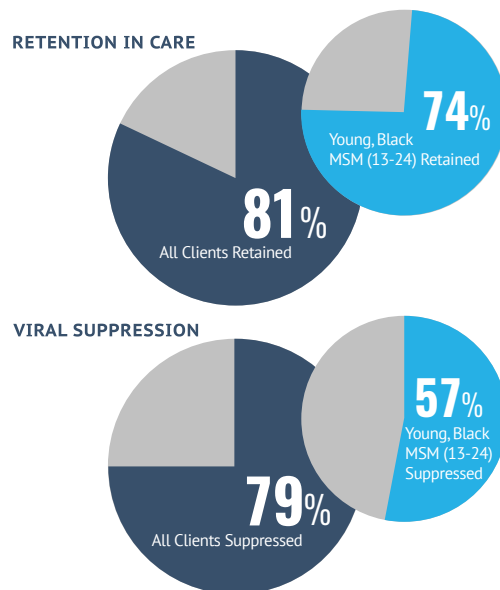


Source: Ryan White Services Report data, 2013

Lack of viral suppression among HIV-positive youth—a sexually active population with inconsistent condom use—may lead to increased HIV transmission.^{35,36} Black, non-Hispanic clients are the least likely of any racial/ethnic group to be virally suppressed. This is particularly noteworthy given high rates of HIV infection among black, non-Hispanic YMSM and black, non-Hispanic young women.

Retention in care is a critical component supporting viral suppression. Youth served through the Ryan White HIV/AIDS Program in 2013 achieved significantly better retention in care than national estimates,³⁴ although gaps continue to exist between percentages of youth retained in care and those who achieve viral suppression. Figure 5 shows the percentages of retention in care among youth in the different age groups; these percentages are particularly higher than the viral suppression percentages in Figure 4.

Figure 6. Retention in Care and Viral Suppression among Young, Black MSM Served by the Ryan White HIV/AIDS Program, 2013



Source: Ryan White Services Report data, 2013

When examining young, black MSM aged 13–24—the most at-risk youth population—retention and viral suppression are both lower than Ryan White HIV/AIDS Program clients overall (Figure 6) and lower than the averages among youth clients. Continued efforts to better reach this population and deliver the services and adherence information they need remains critical to curtailing new infections and moving closer to an AIDS-free generation.

Examples of Successful Interventions

Grantee sites are using a variety of innovative methods to successfully facilitate engagement in care and leadership development among youth and young adults with HIV. Although each operating model is unique, successful programs are striving to be as youth-friendly and accommodating as possible while encouraging youth to take an active role in the HIV community.

Howard Brown Health Center

Mary Brewster and Beto Soberanis of Howard Brown Health Center in Chicago, IL, believe it is critical to engage youth in overall health care, not just HIV care. To facilitate this, all case managers at Howard Brown are certified Affordable Care Act enrollment counselors, allowing them to help clients obtain insurance and learn how to utilize it. “We try to break down any of those barriers you see in more traditional medical settings and make it as accessible to our youth as possible,” says Brewster, the youth program director.

At Howard Brown, a lesbian, gay, bisexual, transgender, and queer-friendly facility, this may entail combining hormonal therapy and HIV treatment into one appointment, absorbing the cost of HIV treatment for youth who are unable to access insurance, or meeting youth off-site. Case managers working specifically with the youth population strive to make their facility a one-stop health center where patients can access all of the medical services they need in one location. If needed, appointments are provided on a walk-in basis, especially for those who are transient or street-based, to make HIV care as simple and accessible as possible.

New York State AIDS Institute

To encourage leadership among youth with HIV, the AIDS Institute in New York has formed a Young Adults Consumer Advisory Committee (YACAC). Youth aged 13–24 meet periodically to discuss relevant and timely issues, including pre-exposure prophylaxis (PrEP), stigma, discrimination, and emotional attachment to pediatric providers. They have the opportunity to provide feedback and recommendations to AIDS Institute staff, as well as to speak directly with clinical providers to voice any concerns. Participants are often paired with older mentors from the AIDS Institute’s adult advisory committee to support their engagement in YACAC, and both encourage and facilitate the subsequent transition to the adult consumer advisory board.

Dan Tietz, the AIDS program manager for consumer affairs, stresses the importance of meeting youth at their level. Logistically, this entails flexible scheduling to accommodate school and other activities, communicating with youth informally through social media and text messages, and hiring dedicated staff that are as young or peer-like as possible. “These youth understand that when they give recommendations, they see tangible results. One of the keys is to let it be their process and respect that process.” Youth seeing their recommendations readily implemented within the clinic has a two-fold result: a more youth-friendly clinic overall, and development of the next generation of HIV leaders. Youth are additionally provided with opportunities to be involved in their care, with the goal of promoting improved self-management and an easier transition into the adult care system.

Children’s Hospital & Research Center Oakland

Because the transition from child-centered to adult care systems is often difficult for HIV-infected youth, patients at the Oakland Children’s Hospital begin preparing early. From ages 17–21, young adults are led through a transition program to ensure they have a full understanding of the HIV disease process, their own medical history, and the importance of medication adherence and engagement in care. “A successful youth program incorporates a pediatric program that has a dedicated HIV youth program for the kids to transition through,” says Stephanie Montgomery at Oakland Children’s Hospital.

Youth at Oakland Children’s Hospital are also encouraged to attend the One Love Conference, a 3-day youth-created, youth-led conference held at a local California college campus. It gives adolescents and young adults an opportunity to engage in discussions and workshops on issues such as finances, relationships, and medication adherence, as well as providing an opportunity to develop leadership skills. The hospital-affiliated Downtown Youth Clinic also focuses on the transition from pediatric to adult systems of care by employing peer advocates to work with youth to identify key goals for not only their health but also for school and careers, thereby critically thinking about their futures and setting themselves up for success.

Characteristics of a Successful Youth Program

While programs vary, certain shared characteristics across sites can help providers refine their work to better reach—and engage—HIV-positive youth. These include:

- ▶ An LGBTQ-friendly environment
- ▶ One-stop shops with health, hormone therapy, and social support services in one location (if not feasible, active referrals to youth-friendly social support settings)
- ▶ Employment of youth-dedicated, youth-friendly staff
- ▶ Accessible location with walk-in appointments and flexible scheduling
- ▶ Uses informal modes of communication, like texting and social media
- ▶ Creates a warm, welcoming environment with social interaction and entertainment in waiting areas
- ▶ Active communication with youth
- ▶ Opportunity for youth to give feedback and have opinions heard
- ▶ Creation of leadership opportunities for youth
- ▶ Access to youth peer support groups
- ▶ Incentives, where possible, such as bus tokens to alleviate the financial burden of transportation
- ▶ Navigators to help youth understand the health care system and enroll them into Affordable Care Act coverage (if applicable)
- ▶ Development of individualized transition plans
- ▶ Early transition planning for adult care
- ▶ Health education
- ▶ Goal-setting (for health, school, career)
- ▶ Connection to youth-friendly activities and conferences to support social networking and skills building

Conclusion

HRSA focuses efforts on youth in a myriad of ways and equips providers with best practices for reaching this population. Through the Integrating HIV Innovative Practices (IHIP) Project, SPNS has created training manuals and curricula around hard-to-reach populations, including youth. Other ways SPNS is evaluating and addressing the needs of HIV-positive youth include a BMSM initiative focused on youth:

The Ryan White HIV/AIDS Program Part B-funded Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men Cooperative Agreement has a special focus on YMSM youth aged 13–24. This project is working to synthesize strategies for reaching and engaging this population and creating technical assistance materials to help the broader Ryan White HIV/AIDS Community.

Additionally, publications such as this report underscore issues among youth as well as strategies for reaching them. Similarly, a forthcoming HRSA CAREAction newsletter on social media includes tips on reaching youth via various online platforms and how to literally meet youth “where they are.”

HRSA encourages grantees to increase their communication and collaboration with one another to create an even stronger safety net for high-risk populations such as youth. For example, the National Quality Center, in conjunction with HRSA’s Division of Community HIV/AIDS Programs, created a Part C and D Collaborative to establish sustainable clinical quality management programs, share best practices across Part C- and D-funded sites, and ultimately improve health outcomes. The Ryan White HIV/AIDS Program has a rich history and a depth of knowledge to share with the broader health care community, just as grantees have much to share with one another.

Ultimately, effectively addressing challenges requires knowing where a need exists, understanding how to address it, and staying the course to see it through. For HRSA, the RSR data highlight client needs and challenges. As the HRSA Living History website essay on youth³⁷ illustrates, the Bureau has a longstanding and unwavering commitment to addressing HIV among young people in the United States. HRSA remains committed to proactively tackling barriers to care to bring HIV-positive youth into care, provide them a seat at the table, and ensure that they have a bright future.

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