

## Serving HIV-Positive Youth

Half of all new HIV infections in the United States occur among people under age 25.<sup>1</sup> Every hour, two Americans aged 13 to 24 are infected with HIV.<sup>1</sup> Moreover, far too many HIV-positive youth are unaware of their HIV status because they have not been tested. Relatively few youth know where to go for HIV counseling and testing. In a nationally representative survey of teens, ages 15 to 17, only 27 percent of sexually experienced youth said they had been tested for HIV and only 48 percent knew “for sure” where they could go to be tested.<sup>2</sup>

Linking HIV-infected youth to health care is difficult. Most HIV-infected youth do not receive adequate health care, even when it is available.<sup>3</sup> Barriers to health care for HIV-infected youth include lack of financial resources and/or insurance, mistrust of health care professionals, difficulty negotiating complex health care systems, complicated medical regimens, a shortage of providers with expertise in both HIV and adolescent medicine, and concerns about confidentiality. Also, fear, denial, and cultural perspectives may contribute to a young person’s reluctance to go for care. However, research pinpoints important components of programs that effectively serve HIV-positive youth.

### Youth-Friendly Services

Youth-friendly services help HIV-positive youth overcome barriers to health care. Youth friendly services offer—

- Flexible hours, including weekends and evenings, to lessen conflicts with school or work
- Walk-in appointments, to encourage youth to use health care services
- Accessibility—through convenient locations, public transportation, tokens and/or travel vouchers, and transportation assistance for rural youth
- Intensive case management to assist young people with complex issues, such as disclosure and partner notification, and to link youth to mental health care, substance abuse treatment, transportation, and housing, as needed
- Active involvement of young people in all aspects of the program’s planning, operations, and evaluation
- Culturally competent staff who are sensitive to youth’s culture and to racial/ethnic cultures as well as to issues of gender, sexual orientation, and HIV status
- Services appropriate to the clientele—for example, street outreach for homeless youth and tailored support groups for gay, lesbian, bisexual, transgender, and questioning (GLBTQ) youth, substance users, and teen parents
- Culturally appropriate services, designed, planned, staffed, and operated, at least in part, by members of the target population
- Décor, materials, and atmosphere that are youthful and welcoming
- Informational materials appropriate to the language(s) and literacy level(s) of the youth served.

### Comprehensive Health Care

Research shows that HIV-positive youth need multidisciplinary case management and care. Such care integrates primary care with HIV-specific care, mental health services, sexual health care and secondary prevention.<sup>3</sup> Moreover, youth usually prefer age-appropriate, “one-stop shopping” in health care settings and from providers who are familiar with their needs.<sup>3</sup> Health care providers’ attitudes, such as respectfulness or its opposite (i.e., condescension towards youth and/or homophobia), appear to be major factors in drawing youth into or deterring them from using the health care system. When working with HIV-positive youth, another significant issue is helping them adjust to their HIV status.

Overall goals of primary care include

- Determining the stage of HIV disease
- Providing ongoing health maintenance
- Monitoring immune function and viral load
- Providing education about HIV and risk reduction
- Providing access to state-of-the-art treatment and to appropriate clinical trials
- Identifying and addressing psychosocial needs.<sup>3</sup>

HIV-positive youth have a wide range of psychosocial needs. They need emotional support to promote quality of life and treatment adherence. They need support to end isolation and to challenge discrimination. They also need food, shelter, and transportation. In addition, HIV-infected youth must deal with the developmental, cognitive, and emotional changes of adolescence. The goals of psychosocial care for HIV-positive youth include

- Identifying and addressing crises (i.e., suicidal behavior, homelessness)
- Providing access to benefits, entitlements, and services
- Promoting adherence to medical regimens
- Assessing and expanding social support
- Supporting youth in self-care and life-enhancing practices
- Identifying and treating chronic problems (i.e., depression, substance abuse)
- Promoting skills to live independently and to make the transition to adulthood
- Reinforcing and sustaining safer sex behaviors
- Promoting harm reduction and encouraging drug treatment.<sup>4</sup>

## Comprehensive Mental Health Services

Providers need to assess the emotional support available to HIV-positive youth. Providers can help youth to identify support systems and available resources. They can encourage youth to use resources and support. Support networks may include family, friends, sexual partners, health care providers, teachers, counselors, clergy, and adult role models. Providers should also assess youth's awareness of and involvement with community-based HIV/AIDS programs and with other HIV-infected people. Working with speakers bureaus, volunteering, and/or participating in HIV community planning groups promotes young people's well-being. HIV-positive youth can also benefit from participating in peer support groups. Such groups reduce the isolation and stigma of HIV and provide emotional support as well.

Many HIV-positive youth struggle with mental illness and substance abuse. These issues may strongly affect how the young person copes with his/her HIV status, including adhering to a treatment regimen. Before implementing the young person's HIV-specific care, providers may need to deal with these issues, either by providing substance abuse and/or mental health care or by linking youth with such services.

## Other issues to consider

In addition to offering youth-friendly services and comprehensive physical and mental health care, agencies serving HIV-positive youth need to consider other issues that affect youth's ability and willingness to seek and profit from health care.

**Respect**—Youth want to be treated with respect. HIV-infected young people may fail to seek needed services or may refuse services if they perceive a lack of respect.

**Confidentiality**—Providers should assure youth that the information they share is confidential. Research shows that fearing their confidentiality will be breached is a major deterrent to many young people's seeking health services. The issue is particularly important for HIV-positive youth, who may experience rejection, discrimination, and/or violence if their confidentiality is breached.

**Disclosure**—Making decisions about disclosure of HIV status is an important step for HIV-positive youth who may have cause to fear rejection and violence from family, friends, and partners. GLBTQ youth may have to confront additional stigma due to their sexual orientation and/or gender identity. Heterosexual youth, infected with HIV through sexual intercourse or injection drug use, may fear disclosing drug use and/or risky sexual behaviors.<sup>4</sup>

Providers should initiate discussions about disclosure and partner notification and inform the young person about the advantages and disadvantages of disclosure. HIV-infected youth may need support and guidance about when and how to disclose their HIV status to sexual partners and whether and how to disclose to family, friends, co-workers, and others. Young people may find assistance from peer support groups in exploring their best options around disclosure.

**Secondary Prevention**—HIV-positive youth need information about how to prevent new sexually transmitted infections (STIs) as well as re-infection with different strains of HIV—any of which could damage the immune system and interfere with health regimens. Secondary prevention offers a chance to empower HIV-positive youth with a sense of control over the future direction of their life and illness. Successful secondary prevention programs promote self-esteem and self-efficacy, build communication and social skills, provide basic information about safer sex and other risk reduction strategies, and offer peer support.

**Treatment adherence**—Youth’s adherence to treatment may be complicated by issues such as denial, fear, misinformation, lack of trust in doctors, doubt about medications’ effectiveness, low self-efficacy, lifestyle, and lack of social support. Adherence may be especially difficult for youth faced with issues, such as homelessness or substance abuse, that force them to deal daily with finding shelter and surviving.

Providers can promote treatment adherence by keeping regimens simple and by working in partnership with the youth to develop individualized treatment plans and strategies that will overcome obstacles to adherence. Regimens should fit an adolescent’s developmental and cognitive stage. When developing a treatment regimen for HIV-positive youth, providers need to consider and address whether the adolescent—

- Believes that medications will help
- Trusts the health care provider
- Has social support
- Has disclosed his/her HIV status and to whom
- Has support systems and resources available
- Is ready to change risk behaviors
- Is ready to change behaviors that will negatively influence the course of HIV illness.

Providers need to reward and positively reinforce youth’s efforts at treatment adherence. Youth may also need encouragement in order to sustain behavior change.

**Medical Insurance**—Paying for care is a significant problem for most young people. A recent study found that one in seven adolescents was uninsured, and the proportion of uninsured youth was even higher among those with a family income below federal poverty lines as well as among African American and Latino youth.<sup>5</sup> Providers can help tremendously by assisting youth to obtain treatment through Ryan White services and Medicaid.<sup>4</sup>

**Housing**—Housing is an essential element in the safety net of HIV-positive youth. Some youth are put out of their homes when their HIV status becomes known. Other youth are at great risk for HIV infection because they are homeless. Many homeless youth engage in survival sex—exchanging sex for money, food, or shelter in order to survive on the streets.

Youth who are infected with HIV are more likely to follow complex medical regimens and to remain healthy if they have a safe place to live, an address where providers can reach them, and a place to keep medications and other necessities. Providers can help by asking questions to ascertain whether youth have stable, safe housing. If a young person is not living in a stable and safe environment, providers can assist by linking youth with social services agencies, shelter services, and AIDS-services organizations (ASOs).

## Meeting the Comprehensive Needs of HIV-Positive Youth

Youth-serving organizations (YSOs) and ASOs both can play integral roles in serving the needs of HIV-positive youth. YSOs generally have a greater understanding of youth and youth culture. ASOs have more experience with care and treatment of HIV-infected people. Through collaborative partnerships and coordinated services, YSOs and ASOs may overcome barriers to care for HIV-positive youth.

## Conclusion

HIV infection in young people is a challenge for youth, health care providers, youth-serving professionals, advocates, and policy makers. Achieving effective and sustainable programs to adequately serve HIV-positive youth is important to assuring the health and development of these youth. HIV-infected youth as well as young people at risk for HIV infection need to be identified in HIV counseling and testing programs and linked to comprehensive mental and physical health care. Youth have a right to services that are affordable, accessible, confidential, and youth-friendly. HIV-infected youth also have a right to be treated with respect.

## Resources for HIV Positive Youth

### National Resources

Adolescent AIDS Program  
Children's Hospital at Montefiore Medical Center  
718.882.0232  
www.AdolescentAIDS.org

National Association of People with AIDS  
202.898.0414  
www.napwa.org

Advocates for Youth  
202.347.5700  
www.advocatesforyouth.org

National Minority AIDS Council  
202.483.6622  
www.nmac.org

AIDS Alliance for Children, Youth and Families  
202.785.3564  
www.aids-alliance.org

National Youth Advocacy Coalition  
202.319.7596  
www.nyacyouth.org

CDC National AIDS Hotline  
800.342.2437 (English)  
800.344.7432 (Spanish)  
800.243.7889 (TTY)

YouthHIV  
A project of Advocates for Youth

### Other Web Site Resources

www.thebody.com  
www.whatudo.org

### State Resources

For resources searchable by state, visit [www.youthhiv.org](http://www.youthhiv.org).

## References

- <sup>1</sup> White House Office of National AIDS Policy. *Youth and HIV/AIDS 2000: A New American Agenda*. Washington, DC: The Office, 2002.
- <sup>2</sup> Henry J. Kaiser Family Foundation. *National Survey of Teens on HIV/AIDS*. Menlo Park, CA: The Foundation, 2000. [<http://www.kff.org/>]
- <sup>3</sup> Futterman D, Chabon B, Hoffman N. HIV and AIDS in adolescents. *Pediatric Clinics of North America* 2000; 47:171-87.
- <sup>4</sup> Ryan C, Futterman D. *Lesbian and Gay Youth: Care and Counseling*. [Adolescent Medicine State-of-the-Art Reviews; v 8, no 2] Philadelphia, PA: Hanley & Belfus, 1997.
- <sup>5</sup> Brindis C et al. *Adolescents and the State Children's Health Insurance Program (CHIP): Healthy Options for Meeting the Needs of Adolescents*. San Francisco, CA: National Adolescent Health Information Center, University of California, 1999.



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