



HRSA CARE ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

JULY 2004

Adolescent Girls and Young Women and HIV/AIDS

The HIV/AIDS epidemic has increasingly become a public health challenge among adolescent girls and young women. Most at risk are those with a history of sexual abuse, poverty, violence, or limited educational and economic opportunities.

One in 4 AIDS cases reported among women in the United States are among people age 29 and younger, compared with about 1 in 6 cases among men. As has often been noted, the reproductive health needs that bring girls and young women into contact with health care providers present a greater opportunity for HIV testing and, therefore, a greater chance of detection.*¹ But this is only part of the story. Sexual relationships between older men and underage women dramatically increase the risk of exposure to HIV and other sexually transmitted infections (STIs). Biologic and physical maturation factors also put younger women at risk for HIV.² Emerging from this rather daunting landscape of risks and challenges, however, are the stories of adolescent girls and young women across the country who have learned to live with HIV disease—women whose courage and perseverance have helped them gain control over their bodies and their lives.

Sex, Drugs, and HIV Among Adolescent Girls and Young Women

Two-thirds of women ages 13 to 24 living with HIV/AIDS were infected through sexual relationships with HIV-positive men. Delayed sexual activity, safer sex practices, and abstinence would dramatically decrease HIV incidence among girls and young women. But, as statistics demonstrate, the barriers to ensuring such practices are often insurmountable for a complex array of reasons. Limited economic opportunity, single-parent homes, and a lack of optimism about the future are each associated with early initiation of sexual activity and risky sexual behavior. Young women who have suffered sexual abuse or coercion are more likely to have early sexual experiences and multiple partners than are young women who have not experienced abuse.³

Early sexual activity has been associated with the use of alcohol and other drugs.⁴ Teenagers who use alcohol are 7 times likelier—and those who use other drugs 5

* Given the time from seroconversion to progression to AIDS, which often spans 10 years or more, it is evident that a large portion of AIDS cases reported among people under age 30 resulted from infection with HIV during their teens.

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This issue of *HRSA CAREAction* is published in collaboration with HRSA's Office of Women's Health (OWH). Working to ensure that the health needs of underserved women and girls are addressed across their lifespan, OWH coordinates women's health-related activities across more than 80 programs. Current projects include the following:

- Publication of the *Women's Health USA 2004 Databook*, a useful resource on current key facts and figures on women's health status and health services utilization.
- Bright Futures for Women's Health and Wellness, an initiative to increase awareness and dialogue regarding preventive health issues for adolescent girls and women, their health care providers, and the community.
- Women's Health in the Pharmacy School Curriculum, an examination of how women's health issues are taught in pharmacy training programs in the United States.

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times likelier—to be sexually active than their nonusing peers, according to a study from the National Center for Addiction and Substance Abuse at Columbia University.⁵ Whatever the reason for entering into a sexual relationship, sexually active young women often have male partners who are older.⁶ As the age difference between sexual partners increases, so does the likelihood that intercourse is unprotected.⁷

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Young women are often unable to protect themselves from HIV because of a fundamental lack of knowledge about how to reduce the risk of infection. Some inaccurately believe that they are protected by “serial monogamy”—the practice of being sexually exclusive with a partner for the duration of the relationship, and then, when that relationship ends, being sexually exclusive with the next partner. Even in areas of high seroprevalence, many young women—and young men—tend to believe that they are not at risk for HIV infection. A 1999 Kaiser Family Foundation survey found that youth “seemed not to connect the dots between infection rates in their communities and their own risks.” Moreover, for most teens surveyed, “their sense of risk is further diminished because they do not personally know anyone *their age* who is HIV positive.”⁸

Even when they know how HIV is transmitted, some adolescent girls and young women are not able to take action to reduce their risk of infection. A 1997 study of 904 sexually active young women ages 14 to 26 who used Texas family planning clinics revealed that

“almost 20 percent perceived that they never have the right to refuse to have sexual intercourse, to ask their partner if he has been examined for an STI, or to say when their partner is being too rough.”⁹ In the survey, African American and Hispanic females in general, and young girls in particular, were most likely to believe that they did not have sexual rights.¹⁰ The desire for safety and intimacy plays a role in these beliefs, as illustrated by another study in which researchers interviewed more than 500 African American female adolescents. The study found that *not* using a condom with a steady partner was often considered a sign of intimacy—a view reinforced by the paucity of visual or musical representations of abstinence or safer sex in entertainment media that target youth.¹¹

Among females living with AIDS, about 20 percent of girls ages 13 to 19, and 29 percent of women ages 20 to 24, became HIV infected through injection drug use (IDU).¹² Little is known about this population. According to providers interviewed for this article and studies of people living with HIV disease, few HIV-

positive adolescents in care contracted the disease through IDU—reflecting the extreme alienation from health care and other services often experienced by substance abusers. Populations in care are much easier to study than those who are not—a fact that may explain why the literature on HIV/AIDS in adolescents and young adults focuses almost exclusively on youth for whom transmission occurred through sexual contact. Despite the shortage of data, it is clear that new strategies are needed for reaching youth who became HIV infected through IDU.

Linking HIV-Positive Youth to Care

Adolescents are the least insured group in the United States and the least likely to receive primary care (including disease prevention) services. The seriousness of this problem is underscored by the experiences of two Ryan White Comprehensive AIDS Resources Emergency (CARE) Act grantees.¹³

The Adolescent AIDS Program at Montefiore Medical Center in New York City and the DAYAM Adolescent HIV Project at the University of Medicine and Dentistry of New Jersey in Newark are

Treatment Adherence: Barriers for Adolescents

Many barriers to treatment adherence are unique to adolescents. Other barriers affect people with HIV of all ages.

- Fear of disclosure of HIV status to family and friends
- Lack of adult or peer support to reinforce adherence
- The conflict between needing to challenge authority figures and needing to depend on adult providers for support in taking highly active antiretroviral therapy (HAART)
- Difficulty accepting the implications of a serious illness
- Difficulty grasping the connection between strict adherence to HAART and prevention of disease progression
- For youth who live in the inner city, fear that they will die from violence, not AIDS
- Lack of a place to store medicines and lack of a daily routine.

Source: Schietinger H, Sawyer M, Futterman D, et al. *Helping Adolescents with HIV Adhere to HAART*. TREAT Monograph. Rockville, MD: Health Resources and Services Administration, HIV/AIDS Bureau; 1999. Available at: <ftp://ftp.hrsa.gov/hab/TeenHAART.pdf>.

two of the Nation's premiere programs serving at-risk and HIV-positive girls and young women. Both programs are funded through the CARE Act Title IV Program for Children, Women, Youth, and Families. Donna Futterman, M.D., is program director of the Montefiore program. Medical providers and community organizations in the Bronx consistently yield the largest source of new patients at Montefiore, Futterman says, stressing the need for ongoing outreach and education to these organizations given their high staff turnover rates. DAYAM's Robert Johnson, M.D., echoes the role of referrals in enrolling adolescent girls and young women in care, noting that his program receives most of its clients from teenage pregnancy programs, where testing is offered as part of routine prenatal care.

But because so many at-risk youth in America are uninsured and lack access to publicly funded primary care programs, referrals are not enough. The Montefiore and DAYAM programs use comprehensive case finding strategies to counter the extraordinary barriers to services that teens often face. The Montefiore program conducts a social marketing campaign ("HIV. Live With It. Get Tested"); publishes a magazine; and maintains a youth-oriented Web site, www.adolescentaids.org. Using a mobile van as a base, DAYAM's peer outreach workers comb neighborhoods and encourage teens to consider HIV counseling and testing.

HIV/AIDS stigma and fear of the life-threatening implications of an HIV diagnosis—as well as a lack of awareness of "teen-friendly" testing facilities—may

The Family Advocacy Care and Education Services (FACES) at Children's Hospital in New Orleans is funded through Title IV of the CARE Act. FACES' Resources for Adolescents Program (RAP) provides comprehensive services to HIV-infected adolescents. FACES has also conducted two studies on how programs can better serve HIV-positive young people. The first, "In Their Own Words," examined adolescents' experiences with being tested and entry into care. In the follow-up study, "Strategies to Engage Youth," researchers conducted qualitative interviews about what youth want in a clinic setting.

A large number of our young women are moms, who were identified as HIV positive when they became pregnant. They are basically young people raising kids; they have a lot of needs and require a lot of support. They may drop in and drop out of care. It is extremely important to build a relationship with them.

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deter youth from seeking counseling, testing, and care.¹⁴ More specifically, adolescent youth may fear that test results will be reported to their parents or do not want to be seen entering a health care site known to be associated with HIV/AIDS.¹⁵

HIV-positive youth are what ethnographers call a "hidden population." They are defined by "covert" characteristics—for example, they are often disadvantaged, homeless, or high school dropouts—and they may engage in high-risk sexual and drug-using behaviors. Case identification among populations estranged from health care—including youth—is difficult and labor intensive. It involves three phases:

1. Engagement and stabilization
2. The moment of testing
3. Posttest counseling.¹⁶

In the first phase, outreach workers typically make contact with individual

youth; establish trust; and help meet basic needs for food, clothing, and shelter. It is only after the young person has been engaged that counseling and testing can take place.

Barriers to Care and Treatment Adherence

The factors that place adolescent girls and young women at risk for HIV infection do not disappear after seroconversion. In fact, those who acquire HIV perinatally and those who acquire it through sexual contact or IDU often share many of the same treatment-retention challenges. Futterman states, "These kids are now facing adolescence and all of the issues that come along with it, such as peer identification, sexuality, the drive for independence, as well as HIV-related issues [ranging from] disclosure to planning a future dealing with medication."¹⁷

Adults find it hard to adhere to medication regimens even when they feel

Using Title IV funds, the St. Louis-based **Project ARK** (AIDS Resources and Knowledge) implements a comprehensive education, support, and resource program called Health and Education for Youth and Young Adults (HEY), which targets teenagers and young adults living with HIV, at risk for HIV, or affected by HIV. Services include counseling and testing, case management, primary care, support groups, and safer sex education.

Women who became infected through statutory rape or sexual abuse often experience delayed anger and a sense of betrayal. These feelings play into their understanding of what happened to them—and how to make the necessary behavior changes to prevent infecting others. They often become infected at 14, 15, or 16, but do not start dealing with those mental health issues until a few years later. Providers must be prepared to deal with the delayed reaction and be ready for anger and depression to surface even after treatment has been going well for a couple of years.

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REACH, the first large-scale study of HIV disease progression in adolescents, found that high levels of stressful life events were associated with high levels of depression and anxiety. Many of the 230 study participants—who were overwhelming female (77 percent) and African American (74 percent)—reported stressful life events within the past 3 months, especially “family financial problems, parental abuse of alcohol, parental arguing and fighting, changing schools, serious accidents, and death in the family.”²²

Because many adolescents with HIV report alcohol and drug abuse,²³ CHRRPY’s Martinez is participating in a longitudinal study funded by the National Institute on Drug Abuse (NIDA) to examine the relationship between substance abuse, mental health disorders, and other impediments to care for HIV-infected adolescent girls and young women. The 4-year project is slated to end in July 2005. Results should shed important light on strategies to promote adherence and retention in care.²⁴

Care Strategies That Work

A mainstay of successful programs is identifying and addressing each client’s most pressing needs, whether physical, emotional, social, or simply logistical. Martinez underscores this point, noting that the most successful strategy for retaining HIV-infected girls and young women in care is to address their psychosocial needs through mental health service and case management.²⁵ Johnson says, “We are very aggressive in finding people if they don’t come back. With each individual we figure out their specific barrier and overcome it.”²⁶

“fine,” but adherence is particularly challenging for most teens. The research in Miami underscores that from the developmental frame of reference of an adolescent girl, it is just not rational to take drugs that have unpleasant side effects, especially if those side effects threaten to “take her out of action with her peer group.”¹⁸

The stigma that prevents teens from accessing counseling and testing services also hampers efforts to retain them in care. For teenagers, any stigmatization is unacceptable because it carries the risk of exclusion from the all-important peer group. Researchers have heard girls say, “I would rather die than let anybody know.”¹⁹

Futterman and Johnson, along with Jaime Martinez, M.D., of the CARE Act–funded

Chicago HIV Risk Reduction Partnership for Youth (CHRRPY), all emphasize the mental health needs of the girls and young women under their care and the importance of including counseling as part of a comprehensive package of services. Futterman has written, “Case studies of adolescents and young adults with HIV indicate a high prevalence of depression, bipolar disorder, and anxiety, often predating their HIV diagnosis.”²⁰

Research supports their concerns. A study of 21 HIV-positive young women under age 25 enrolled in care at the Whole Life mental health–perinatal HIV care project in Miami found that nearly one quarter reported mental health issues that warranted treatment, including psychiatric diagnoses, substance abuse, trauma-related issues, and psychological distress.²¹ Data from Project

The quality of the provider–patient relationship is crucial and can tip the scale in favor of treatment compliance. The Whole Life program provides a telling example of a young pregnant woman who was skeptical about the need to take medication to protect her unborn baby from HIV transmission. She stuck with the regimen because of her warm relationship with the nurse educator, who worked with the case manager to obtain diapers and a stroller—items the young woman had identified as her most urgent needs.²⁷

In addition to psychological concerns, adolescent girls and young women often face other obstacles to care, including lack of child care, lack of transportation, the logistics of navigating large hospital systems, and complicated treatment regimens. Although programs often can ease transportation needs by sending taxicabs (and providing bus tokens for later visits), other needs are more complicated. Child care, for example, is a critical need for any program that works with adolescent girls and young women. When asked to remark on the differences between the barriers female and male adolescents face in entering treatment, DAYAM's Johnson immediately points out, "Most of the girls have children, and so one big barrier is what to do with their children while they are at the clinic."²⁸ Many programs have addressed child care needs by offering onsite babysitting.

To help clients overcome the huge hurdle of showing up for the first visit, programs must demonstrate persistence and creativity. Confronting a waiting room full of people in various stages of HIV disease, especially on the first visit to

Helping Adolescents Cope With HIV/AIDS: What the Provider Can Do

- When a teen receives an HIV diagnosis, providers should "instill a sense of hope and encouragement."
- Help teens make decisions about disclosure of HIV status to parents, friends, and sexual partners.
- Help adolescents understand asymptomatic HIV infection and learn the meaning of changes in viral load and CD4 counts.
- Help teens cope with becoming symptomatic; some young people become despondent, whereas others rally to the challenge. Providers should explore the meaning of symptoms, correct misperceptions, and ensure that each teen has adequate social support.
- Help teens prepare for death when they are ready. "When clinically appropriate, providers can help adolescents explore their feelings about dying by discussing options for dying at the hospital or at home, talking about funeral and memorial services, and exploring child custody or permanency planning with adolescent parents."

Source: Adapted from: Futterman D. Adolescents. In: Anderson JR, ed. *A Guide to the Clinical Care of Women With HIV, 2001, First Edition*. Rockville, MD: Health Resources and Services Administration; 2001, p. 337. Available at: ftp://ftp.hrsa.gov/hab/Guide_01_ChptXI.pdf.

a clinic, can be traumatic. In the Whole Life program, social workers help by identifying new patients, introducing themselves, and escorting them to a private area for their initial interview.²⁹ In one program, social workers talk to each client before the first visit and provide their beeper numbers so that if the client gets lost in the hospital maze, she can call for assistance.³⁰

Programs have found it helpful to have peer buddies available to talk with teen girls and young women and to offer social support groups. Martinez points out that in his clinic, mixed-gender groups did not work well; the concerns of the mostly gay-identified young men did not match the issues faced by the

young women, most of whom were mothers. The solution was to offer girls-only groups and provide educational programming that appealed to the young women. Martinez observes that while young men (who were primarily infected through same-sex sexual behavior) use the CHRRPY clinic as a place to socialize, young women are more socially guarded. Female teens are more socially isolated even within their home communities; Martinez believes this isolation impedes their ability to take care of themselves.

To help ward off defeatist or fatalistic thoughts about the future, providers should encourage their young patients to focus on the here-and-now. Dodds has

recommended “facilitating a safe space for venting and expression of raw emotion and worst fears; validating her feelings; repetitiously answering questions; elucidating choices; identifying and rallying her systems of support; reframing what appears to be hopelessness into developmentally appropriate frameworks of hopefulness.”³¹

The first step in improving treatment adherence is to build trust with young clients and assess their readiness to stick to a medication regimen. Futterman states, “The first step is to really understand where the young person is with her meds; too often we start with practical first steps about how to remember to take medications, and that’s not where she is.”³² Once readiness has been established, the secret to adherence is limiting the dosing to once or twice daily.³³ (For more information, see HRSA’s publication *Helping Adolescents with HIV Adhere to HAART*, available at <ftp://ftp.hrsa.gov/hab/TeenHAART.pdf>.)

According to Dodds, providers can help adolescents who are prone to concrete thinking, especially those who are inexperienced in problem solving, by “limiting decisions to two options: ‘Would you like to come to your next appointment on Monday or Wednesday?’ rather than the open-ended, ‘When can you come back?’”³⁴ The chaotic lives of most HIV-infected youth present additional obstacles to keeping appointments. Adolescent AIDS programs must accept drop-ins and maintain office hours that do not conflict with school or work schedules. Martinez notes that even though drop-ins play havoc with the clinic’s schedule, it is essential to provide services to youth whenever they appear.³⁵

The Importance of Primary Care Physicians

Futterman observes, “HIV is very challenging medically, and creating a vaccine is uncertain. But one thing that is in our grasp is the ability to find these young people and get them into care. Some of

the new strategies from CDC and HRSA to bring testing more routinely into the health care system are really good ways to do this.”³⁶ By bringing HIV fully into primary care doctors’ purview, all adolescents will benefit. Those who are HIV positive can be identified and linked to care. Those who are HIV negative can feel relieved and focus on ways to remain uninfected. And for teens who are not sexually active, the discussion with their doctor “provides an opportunity to talk about sexual readiness, delaying intercourse, and low-risk ways to explore intimacy.”³⁷

Unfortunately, many at-risk and HIV-positive adolescent girls and young women do not have a primary care provider—and will not have one until reproductive health concerns or symptoms from HIV or other illnesses bring them into contact with the health care system. Even then, the primary care visit may be a missed opportunity. Data from the Youth Risk Behavior Survey show that “less than half of female and only a quarter of male students who reported having received preventive services had discussed the prevention of the outcomes of risky sexual behavior.”³⁸ Clearly, primary care providers serving adolescents can and should use the office visit as a prime opportunity to raise these important issues—and to follow up with HIV testing as appropriate.

Once HIV-positive young people are identified, they need to receive medical care and support services. While some will be fortunate enough to receive care in the comprehensive, adolescent-focused programs described in this article, most will not. In those cases, the

Clinical Trials

The **Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN)** (www.atnonline.org/) is a national, collaborative clinical trials network established by the National Institute of Child Health and Human Development to conduct clinical trials and related research both independently and in collaboration with existing research.

ClinicalTrials.gov (www.clinicaltrials.gov/ct) provides regularly updated information about federally and privately supported clinical research in human volunteers. ClinicalTrials.gov, a service of the National Institutes of Health, provides information about a trial’s purpose, eligible participants, locations, and whom to contact for more details. To find clinical trials for adolescents, use the “focused search” interface.

The **Wayne Wright Resource Center** provides comprehensive services to HIV-positive and at-risk adolescents and young adults in Boston. The center's HIV Support Services program hosts POZ Young Women, a twice-monthly, peer-led social support group for young women living with HIV/AIDS. Through a Title IV subcontract with the Boston Medical Center Children's AIDS Program, the Center's HIV Support Services program offers peer-led discussion groups for perinatally infected young men and women.

We know that disclosure and stigma are difficult. We have to address disclosure and behavior change in young people with HIV. We may have expectations that they are practicing safer sex, but what we really need to do is create a space to allow these young people to talk about their random, normal acts of adolescence.

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systems they enter must be adapted to provide a "youth-centered" approach "by such basic accommodations as offering flexible hours and low or no payment for services and care as well as providers who are knowledgeable about working with adolescents."³⁹

Risk Reduction

All programs serving HIV-infected adolescents dedicate some portion of each clinical visit to a discussion about abstinence, family planning, and sexual risk reduction. Girls are prescribed contraceptives as appropriate, tested for pregnancy, and reminded of the importance of condom use for preventing disease transmission. If they become pregnant, they are provided information regarding prevention of vertical transmission.

Despite regular discussions about sexual risk reduction and family planning, HIV-positive adolescent girls and young women do have unprotected intercourse

and do have unplanned pregnancies. One study of HIV-infected female adolescents found that most reported that they continued to have unprotected sex despite knowing their HIV status.⁴⁰ According to Nina Colabelli, a pediatric nurse practitioner at the Francois-Xavier Bagnoud Center in Newark, NJ, who has been working in the field of pediatric AIDS since 1987, adolescents who are infected with HIV perinatally have the same challenges and struggles with safer sex and disclosure as do teens who acquire the infection sexually or through injection drug use. They are as curious about their sexuality and sexual relationships as any other adolescent, and if they do not feel sick, it is easy for them to forget they are HIV infected, especially during a sexual encounter.⁴¹

Conclusion

Reaching HIV-infected girls and young women; getting them into care; meeting their physical, emotional, and social

needs; helping them adhere to their treatment regimen; and encouraging ongoing sexual risk reduction is a tall order. It is not, however, an impossible task. The programs profiled here and others—many of which receive funding from HRSA—have blazed trails.

Johnson, who has worked for years with HIV-infected young people and has a deep appreciation of their needs, offers the following advice: "The most important thing in caring for teens is flexibility. Understand you won't be successful with teens unless you are willing to modify your system to fit their lives. Too often in medicine it is the other way around: We expect the patients to fit our system. You have to understand, this disease isn't as important to them as it is to us. They don't think they are sick. So we have to be the ones to make the modifications."⁴²

The list of barriers, challenges, and issues HIV-infected adolescent girls and young women face can be daunting—for both patients and providers (see box, p. 2). It is vital to remember that these women also have amazing strengths. They have survived, even thrived, in very difficult circumstances, often while caring for their own children. As Martinez emphasizes, "Stress the strength that these females have. Find out what skills they already have in negotiating sexual relationships, in taking care of themselves and their children. Help them focus on and recognize those strengths, to build their confidence that they can draw on those strengths to cope with HIV."⁴³



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