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AIDS Policy Center
For Children, Youth & Families

May 12, 1999

Todd Summers
Deputy Director
White House Office of National AIDS Policy
736 Jackson Place
Washington, DC 20503

Dear Mr. Summers:

Thank you for registering to attend the National Leadership Forum on Youth and HIV Prevention, sponsored by AIDS Action and AIDS Policy Center for Children, Youth & Families. The event will take place from 9:00am to 5:00pm on Friday, May 21, 1999, at the Renaissance Washington Hotel in Washington, D.C.

The desired outcome of the National Leadership Forum is to develop program and policy recommendations for community-based organizations, state and local health departments, and other organizations to help engage high-risk youth in voluntary HIV testing. About 35 community service providers, young people, federal officials, and representatives of national organizations have confirmed that they will attend the event.

Enclosed you will find a draft conference agenda for the Leadership Forum. As you can see on the agenda, we will spend a significant portion of the day working in three small groups. Group A will discuss outreach strategies to engage youth in HIV testing, including media campaigns. Group B will discuss strategies to make HIV test sites more accessible and appropriate for youth. Group C will discuss national public policy and legal issues related to youth and HIV testing. In order to assure that each group will be about the same size and have a good mix of backgrounds and expertise, we have pre-assigned each participant to a small group. We would like for you to participate in **Group C**. If you do not wish to participate in this small group, please notify Clark Moore at AIDS Policy Center as soon as possible.

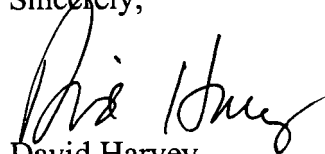
We have also included some important background materials on youth and HIV testing. Please take some time before May 21 to review these materials carefully. If you would like to bring additional materials for participants in the National Leadership Forum, please feel free to do so. Be sure to bring at least 40 copies of your materials.

Please refer to the enclosed logistical information sheet for information on the hotel location and other logistical matters. You are responsible for making all travel and transportation arrangements.

After the National Leadership Forum, we hope that you will also attend AIDS Policy Center's annual conference, Voices '99, which will take place May 22-25 at the same location. On Saturday, May 22, there will be an all-day Youth Forum, a day of empowerment, skills-building, and policy dialogue for young people. The main body of the conference will take place from Sunday, May 23 to Tuesday, May 25. To register for Voices '99, please contact Mary Partlow at mpartlow@aidspolicycenter.org or (202) 785-3564.

Again, thank you for registering for the National Leadership Forum on Youth and HIV Prevention. If you have any questions, please contact Clark Moore at AIDS Policy Center at cmoore@aidspolicycenter.org or (202) 785-3564.

Sincerely,



David Harvey
Executive Director
AIDS Policy Center



Daniel Zingale
Executive Director
AIDS Action

National Leadership Forum on Youth and HIV Prevention
Friday, May 21, 1999
Renaissance Washington Hotel
999 Ninth Street NW
Washington, D.C.

PRELIMINARY AGENDA

- 9:00-9:30** **Welcome and Introductions**
- 9:30-10:00** **State of the HIV Epidemic among Youth**
- 10:00-10:30** **Youth Participation in HIV Testing: An Overview**
Presenter: Donna Futterman, MD
Montefiore Medical Center, Bronx, NY
- 10:30-10:45** **Youth and HIV Testing: Legal Issues**
Presenter: Abigail English, JD,
Center for Adolescent Health and the Law, Chapel Hill, NC
- 10:45-11:15** **Group Discussion and Brainstorming: Issues and Strategies**
- 11:15-11:30** **Charge to Small Groups**
- 11:30-3:00** **Small Groups Meet (*box lunch provided*)**
- Group A: Outreach strategies
 - Group B: Accessibility and appropriateness of HIV test sites
 - Group C: National public policy and legal issues
- 3:00-3:15** **Break**
- 3:15-3:45** **Small Group Report-Outs**
- 3:45-4:30** **Group Discussion and Brainstorming: Issues and Strategies for Specific Youth Populations at High Risk**
(including GLBT youth, youth of color, young women, and others)
- 4:30-5:00** **Wrap-Up**

National Leadership Forum on Youth and HIV Prevention
Friday, May 21, 1999
Renaissance Washington Hotel
Washington, D.C.
9am - 5pm

LOGISTICAL INFORMATION

Travel Arrangements

Debbie Bucia of Executive Travel can assist you with making travel arrangements. She can be reached at dbucia@exectravel.com or (800) 704-9883, ext. 223.

Hotel Information

The National Leadership Forum on Youth and HIV Prevention will be held at the Renaissance Washington Hotel, 999 Ninth Street NW, Washington, DC. The hotel phone number is (202) 898-9000.

To make a reservation at the Renaissance Washington Hotel, call the reservations line at (800) 228-9290. If the Renaissance Washington Hotel is full, you may also contact one of our "overflow" hotels, both of which are located nearby. These hotels are the Henley Park Hotel, at (800) 222-8474, and the Morrison Clark Inn, at (800) 228-9290. When calling any of the hotels, be sure to say that you are attending the "AIDS Policy Center/Voices" conference.

As noted on the invitation letter, we request that you seek funds from your organization to pay for your hotel and travel expenses. If you are unable to pay for the cost of hotel or travel, please contact Clark Moore of AIDS Policy Center at (202) 785-3564.

Driving Directions to the Renaissance Washington Hotel

From the North (New York, New Jersey, Pennsylvania):

Take I-95 South, Baltimore Washington Parkway toward Washington. Take New York Avenue. At 5th Street NW, stay to the right which will change into L Street NW. Take L Street NW, to 9th Street, NW, just past New York Avenue. The Renaissance Washington Hotel is immediately on the left.

From the South (Virginia):

Take I-395 North to Washington. Take the 12th Street NW exit. Then take 12th Street NW to New York Avenue. Make a right onto New York Avenue. Go to 9th Street, NW and turn right. The Renaissance Washington Hotel is immediately on the left.

From the West (Dulles, VA):

Take I-66 East to Constitution Avenue and take Constitution to 12th Street NW. Make a left onto 12th Street NW, and take it to New York Avenue (7th traffic light). Make a right onto

New York Avenue. Take New York Avenue to 9th Street NW. Turn right. The Renaissance Washington Hotel is immediately on the left.

From the East (Annapolis, MD):

Take 50 West to New York Avenue. At 5th Street NW, stay to the right. It will change into L Street NW. Take L Street NW, and make a left turn onto 9th Street NW. Once across New York Avenue, the Renaissance Washington Hotel is immediately on the left.

From I-270 (Frederick, MD):

Take I-495 Beltway West (Northern Virginia) to George Washington Parkway. Take George Washington Parkway to I-395 North (14th Street Bridge). Take I-395 North to 12th Street NW. Take 12th Street NW to New York Avenue (7th traffic light). Make a right onto New York Avenue. Take New York Avenue to 9th Street NW. Turn right. The Renaissance Washington Hotel is on the left.

Other Transportation

Washington Flyer Shuttles: Washington Flyer provides shuttle and taxi service from the major airports directly to Renaissance Washington Hotel. The Flyer operates every half-hour, non-stop, 7 days a week from 5:45am to 9:25pm. Information: (703) 685-1400.

Washington Metro: the metro system stops 2 blocks from Renaissance Washington Hotel. The Gallery Place/Chinatown Metro stop is on the Red, Green, and Yellow lines. Hours of operation: Weekdays: 5:30am to midnight. Weekends: 8:30am to midnight. Information: (202) 637-7000.

Maryland Commuter Service Transit (MARC): MARC provides affordable transportation from Baltimore, BWI Airport, Camden Yards (Orioles Park) to Washington's Union Station. The Union Station Metro stop is two stops away from Renaissance Washington Hotel (Gallery Place/Chinatown). Information: (800) 325-7245.

From Dulles International Airport

Taxi: Washington Flyer taxi cabs are available for approximately \$45 plus tip. Travel time is 45 minutes. Information: (703) 685-1400.

Shuttle: Washington Flyer express Shuttle Buses operate every half-hour directly to Renaissance Washington Hotel: the fare is \$16 one-way or \$32 round-trip. Travel time is 45 minutes. Information: (703) 685-1400.

Public Transportation: Public transportation is not a convenient option from Dulles International Airport.

From Washington Reagan National Airport

Taxi: DC, MD, and VA cabs are available; 4.5 miles to downtown Washington; approximately \$12-\$13 plus tip. Travel time is 20 minutes.

Shuttle: Washington Flyer Express to Renaissance Washington Hotel. Fare is \$8 one-way or \$14 round-trip. Travel time is 30 minutes. Information: (703) 685-1400.

Metro: there is a metro station at National Airport. Take the Yellow Line to the Gallery Place/Chinatown stop. Take the 9th Street NW exit and walk 2 blocks north to Renaissance Washington Hotel. Information: (202) 637-7000.

From Baltimore Washington International Airport (BWI)

Shuttle: BWI Super Shuttle provides service from BWI to Renaissance Washington Hotel upon request. The fare is \$24 for the first person and \$5 for each additional person. Information: (202) 562-1234.

Taxi: BWI is a one-hour drive from the Renaissance Washington DC Hotel. Taxi fares range from \$55 to \$60.

Public Transportation: BWI Airport transportation provides free shuttle bus service every half hour to the Maryland Commuter Service (MARC). The MARC train leaves BWI approximately every half hour. Take the BWI train to Washington's Union Station. At the station, take the metro Red Line to the Gallery Place/Chinatown stop. Take the 9th Street exit and walk 2 blocks north to Renaissance Washington Hotel. The MARC fare is \$4.50 one-way and \$8 round trip. The Metro fare is \$1.10. Travel time is 50 minutes. MARC Information: (800) 325-7245. Metro Information: (202) 637-7000.

From Union Station/Amtrak

For guests coming to Washington via Amtrak, Union Station is just 2 Metro stops from Renaissance Washington Hotel. Take the Metro Red Line to Gallery Place/Chinatown stop. Take the 9th Street NW exit and walk 2 blocks north to Renaissance Washington Hotel. Information: (202) 637-7000.

From the Greyhound Bus Station

Taking a taxi from the Greyhound Terminal is suggested. The fare is \$4.90 plus tip. Travel time is 10 minutes.

POSITION STATEMENT

Youth & HIV Testing

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FOR CHILDREN, YOUTH & FAMILIES**
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**AIDS Policy Center
for Children, Youth & Families**

Families and youth affected by AIDS, service providers, clinical researchers, advocates and educators launched AIDS Policy Center (APC) in March 1994. APC is a national leader in HIV/AIDS public policy research and analysis, training and technical assistance and information dissemination. With 300 member programs in 26 states, the District of Columbia and Puerto Rico, it is the only national organization with a sole focus on children, youth and family HIV legal and policy issues.

Purpose of Publication

In 1995, APC started a series of "policy briefs", "reports" and "position statements" on important issues facing children, youth and families affected by HIV and AIDS. Due to the importance of youth and HIV testing issues, the adolescent HIV policy advisory committee of the APC board of directors began to research and write the following position statement in early 1995 in order to help youth service providers, HIV/AIDS organizations and others concerned about youth and HIV to work toward better HIV counseling and testing programs for youth. This publication represents one of the first APC position statements released by the Center and includes program and public policy recommendations. Although the capabilities of agencies vary throughout the United States, it is hoped that this report can serve as a guide for public policy and programs related to this important topic. Contact APC for additional copies of this report or for a list of other reports and policy briefs released by the Center.

April, 1996

Sheri Saltzberg, MPA
President, Board of Directors

David C. Harvey, MSW
Executive Director

**Adolescent HIV Policy Advisory Committee
APC Board of Directors**

Comments and feedback on the usefulness of this position statement are welcome and should be sent to Janet Shalwitz, M.D., Chair, Adolescent HIV Policy Advisory Committee at APC, 910 Seventeenth Street, NW, Washington, DC 20006. The committee would like to acknowledge the contributions of Brett Rudy, M.S., Chris Hall, and Clark Moore to this document.

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AIDS Policy Center for Children, Youth & Families
Position Statement on Youth and HIV Testing

Introduction

HIV seroprevalence data consistently indicate significant and increasing levels of HIV infections among adolescents. As early intervention options for HIV positive youth have become more available, it has become increasingly important to diagnose these youth and link them to appropriate care. It is clear that all youth should have access to age-appropriate and culturally competent HIV counseling and testing. It is also important to protect the rights of young people by requiring their written, informed consent for testing and by maintaining strict confidentiality.

Background

During the transition from childhood to adulthood, adolescents undergo significant changes in physical, sexual, cognitive and psychosocial development. They explore and develop their attitudes, values, and goals and begin to assert their independence from parents and other authority figures. Their general tendency is to be present-oriented and have feelings of invulnerability. They also frequently experience feelings of isolation, anger, hopelessness, and low self-esteem. As a result of these and other factors, youth are likely to experiment with behaviors that may lead to infection with HIV.

Numerous studies report high levels of HIV risk behaviors among youth. Centers for Disease Control and Prevention (CDC) surveys indicate that about three-fourths of high school students have sexual intercourse before they graduate, and less than half of sexually active youth report consistent condom use (1995a). High rates of unprotected sexual intercourse among adolescents are also indicated by data on sexually transmitted diseases (STDs) and pregnancy. Each year, about three million teenagers are infected with an STD and over one million teenagers become pregnant (CDC, Division of STD/HIV Prevention, 1995; Hofferth, 1987; Spitz *et al.*, 1993). Drugs and alcohol are significant direct and indirect risk factors for HIV. In a recent national survey of high school students, 1.4% reported having injected an illegal drug (Kann *et al.*, 1995). The use of non-injection drugs and alcohol is widespread among youth and is associated with risky sexual behavior (Fortenberry, 1995; Millstein & Moscicki, 1995).

HIV infection is the sixth leading cause of death for young people ages 15-24 in the United States (CDC, National Center for Health Statistics, 1993). As of October 1995, 2,184 adolescents ages 13-19 and 17,745 young adults ages 20-24 had been reported with AIDS, and most of the young adults with AIDS were infected with HIV as teenagers. Among men ages 20-24 with AIDS, 63% are men who have sex with men, 13% are injection drug users, and 11% are men who have sex with men and inject drugs. Among women in the same age group, 50% acquired HIV through sex with men, 33% are injection drug users, and 14% are of unidentified or unreported risk. Compared to adults over 25, higher percentages of young adults ages 20-24 with AIDS are female (23% vs. 13%) or were infected through heterosexual sex (14% vs. 7%). African Americans and

Hispanics are disproportionately represented among young adults ages 20-24 with AIDS, with over 59% of reported cases (CDC, 1995b). The total number of HIV infected youth is unknown; however, it has been estimated that people under 22 years old accounted for 25% of all new infections from 1987 to 1991 (Rosenberg *et al.*, 1993). Because there is delay of up to ten years before individuals infected with HIV develop AIDS, many HIV positive youth are unaware that they have been infected (Lindgren *et al.*, 1994).

Although many young people are either already infected or are at serious risk for HIV, relatively few of them have ever taken an HIV test. Many youth are tested only in the context of other medical care; for example, many pregnant young women are tested during prenatal care. Furthermore, a large portion of youth tested for HIV fail to return for their results. In a study of publicly funded test sites, only 45% of all teenagers who were tested for HIV returned to learn their results (Valdiserri *et al.*, 1993). Researchers have identified numerous barriers to counseling and testing, including perceived lack of risk for HIV, anxiety about dealing with a positive test result, concerns about confidentiality and discrimination, and fears about the impact of the results on relationships and social status (Phillips & Coates, 1995). For many young people, a lack of awareness about the benefits of early treatment for HIV and access to youth-friendly and culturally sensitive HIV test sites and health care services are also significant barriers.

All youth should have access to voluntary HIV counseling and testing with informed consent. The primary purpose of offering HIV counseling and testing to young people should be to identify HIV infected youth and to link them to medical and psychosocial care. Many HIV positive youth enter care only once they are considerably immunosuppressed or have developed HIV-associated symptoms (Rogers *et al.*, in press). A study in New York found that almost half of the youth who presented to an adolescent HIV program had a CD4 count below 500/mm³, and 22% presented with a count below 200/mm³ (Futerman *et al.*, 1993). Had these youth been identified earlier, they could have taken advantage of early intervention options, including initiation of anti-retroviral medication, prevention of opportunistic infections, and reduction of perinatal HIV transmission. It has been postulated that such delays in diagnosis and treatment may result in a foreshortened survival of youth with HIV disease (Remafedi & Lauer, 1995). Counseling and testing programs can also be an access point into primary care and psychosocial services for HIV negative youth. Finally, pre- and post-test counseling may provide a setting for HIV education, risk assessment and risk reduction. Many youth benefit from the opportunity to ask questions and discuss their concerns about HIV/AIDS with a test counselor. However, HIV testing is not a substitute for comprehensive health promotion and risk reduction programs. Most research indicates that the HIV testing process alone does not lead to lasting behavior change (Futerman *et al.*, 1990; Higgins *et al.*, 1991; Ickovics, *et al.*, 1994)

It is particularly important to provide the option of HIV counseling and testing for all youth because many HIV infected young people do not report falling into a "high risk" group. For example, in a study of HIV test sites in Houston, almost half of the

teenagers who tested positive for HIV failed to acknowledge a risk factor (Ilegbodu *et al.*, 1994). In a Washington D.C. seroprevalence study, only 38% of youth testing positive for HIV had been identified by clinicians as "high risk" (D'Angelo *et al.*, 1991). Therefore, information about HIV counseling and testing options should be an important part of broad-based HIV education and prevention programs offered through schools and community-based organizations. Special outreach efforts must also be made to offer HIV education, counseling and testing to youth who are at particularly high risk for HIV, such as young men who have sex with men, injection drug users, and youth who engage in survival sex.

Program Recommendations

HIV counseling and testing should be made accessible to all young people. Youth who are sexually active should be encouraged to consider being tested.

Health care providers, including school-based clinics, managed care organizations, community health centers, STD clinics, and prenatal clinics, should examine their current HIV testing policies and procedures to ensure that voluntary HIV counseling and testing are available and accessible to all young people.

HIV counseling and testing must be offered in an environment that youth perceive as supportive and non-judgmental. Therefore, counselors must be trained in the developmental and psychosocial characteristics of adolescents. They must also be sensitive to the unique cultural issues and characteristics of youth, particularly with regard to race, ethnicity, gender, sexual orientation, and lifestyle.

Youth must receive thorough, individualized pre- and post-test counseling. During pre-test counseling, counselors must assess the youth's coping skills and discuss strategies for dealing with the test results. HIV test counselors should provide the option of multiple pre-test sessions when appropriate. Multiple pre-test sessions may enhance the effectiveness of the testing process as a risk reduction tool and increase the rate of return for post-test counseling.

Confidential HIV counseling and testing may be optimal for most youth because it can help improve rates of return for post-test counseling and facilitate linkages to care. However, all youth should have the option of anonymous or confidential counseling and testing. Prior to testing, counselors must explain the differences between anonymous and confidential testing, what the results of the test do and do not mean, and who will have access to the results. HIV testing should be conducted only with the youth's written, informed consent. Service providers must understand and adhere to local, state and federal laws pertaining to consent and confidentiality for HIV counseling and testing.

Peer counselors can often help make youth feel more comfortable with the HIV

counseling and testing process. They may be able to talk to youth in language they understand and may serve as a resource for safe disclosure of risk behaviors. In order to ensure that they provide accurate information and receive adequate guidance, peer counselors should be thoroughly trained and supervised.

HIV testing sites must have effective links to appropriate care and support services.

Young people who test positive should be referred to youth-sensitive HIV services, including medical and psychosocial care. Those who test negative should be educated about the HIV antibody "window period" and encouraged to re-test as appropriate. They should also be informed about services providing ongoing risk reduction education and support as well as other needed health and social services.

Young people should be encouraged to discuss their decision to get tested for HIV with a parent or other supportive adult. Parents can play a key role in providing guidance, support, and nurturing to adolescents, and can be of particular importance to young people who test positive. Counselors should help young people who do not have supportive parents to identify another appropriate adult.

Public Policy Recommendations

Federal and state laws should require that adolescents or young adults who are tested for HIV provide written, informed consent and receive individualized pre- and post-test counseling. Most adolescents are capable of understanding the risks and benefits of medical procedures, and should therefore be able to provide independent consent for HIV testing (English, 1992). State laws should give adolescents the explicit rights to provide independent consent for HIV testing and authorize any disclosure of test results.

Federal, state and local governments must assure that age-appropriate medical, mental health, and support services are available and accessible for all youth with HIV.

The Centers for Disease Control and Prevention (CDC) must only fund HIV counseling and testing programs that are anonymous or confidential and have links to youth-sensitive health services, including medical and psychosocial care. The CDC-funded HIV Prevention Community Planning Groups (CPGs) should make youth a priority for HIV education, prevention, counseling and testing programs.

National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), and CDC should devote additional resources to research on youth and HIV counseling and testing issues, including attitudes, access, participation, and outcomes. Further research is also needed on innovative health service models, youth risk behaviors, behavior change, and HIV prevalence.

AIDS Education and Training Centers (AETCs), HRSA, CDC, and other federal, state, and local agencies must fund and support programs which provide special training

and assistance for health care providers on improving the quality and availability of HIV counseling and testing for youth.

CDC should issue guidelines and recommendations on HIV counseling and testing of youth, based on the input of HIV-positive young people and experienced youth providers.

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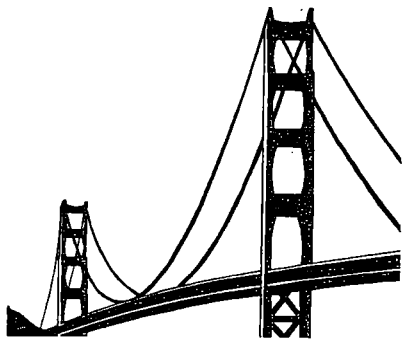
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bridges

Linking those who work with HIV-affected youth

Winter 1997

A Publication of Health Initiatives for Youth

Volume 3, Number 1

young people and HIV testing

At a time when long-held assumptions about HIV are being called into question, the role of testing — a key element of both prevention and care — stands at the center of some complex new debates. Powerful treatments may increase the urgency for infected people to learn their status, while new technologies may make testing more rapid and accessible for hard-to-reach populations such as youth. As home collection kits, oral swabs and protease inhibitors alter the HIV landscape, adolescents and young adults stand to be among the groups most profoundly affected. But even leaving aside these dramatic and far-reaching changes, a fundamental question remains the same: What is the value of HIV testing for youth?

Since its introduction in 1985, testing has been a component of HIV outreach, prevention and care programming. In addition to identifying infected individuals, the testing process can, ideally, provide referrals or direct linkages to psychosocial and medical services. It also offers the opportunity for counseling about reducing risks

and maintaining health for people regardless of their test result.

The importance of testing as a component of HIV care and treatment programs is fairly straightforward. Its value as a prevention intervention, however, is somewhat less clear. While the test site counseling session can

reinforce the need for safer practices, the testing experience by itself does not change behavior, and research has shown limited effects of counseling and testing on long-term behavior change.^{1,2}

Because behavior change is complex and gradual, HIV testing and

(continued on page 2)

counseling can rather be viewed as an important part of a larger process that includes other activities to support risk reduction efforts. In this context, the test site encounter is an opportunity for a counselor to raise important issues, rather than resolve them; in many cases, the most important element of the session may be a referral that connects a person with a more long-term service such as individual counseling, primary care, an ongoing support group, or recreation program.

In testing programs that serve youth, the most crucial component is non-judgmental, youth-sensitive counseling. Depending on his or her level of cognitive development

can help a young person place the risk of HIV in a broader context, and at the same time better understand and reduce risks. On a larger level, the act of testing can represent an important step in a young person's emotional and psychological development. In taking that step, a young person connects past actions with future consequences, weighs alternatives, thinks abstractly, and makes a decision that may affect his or her long-term future. The test site counselor can play an important role in this process.

The assurance of confidentiality is also key to HIV testing for youth. Anonymous testing, in which no name and a minimum of personal

The act of testing can represent an important step in a young person's emotional and psychological development.

and maturity, a young person may not fully understand the meaning of a test result or its implications, and counselors must be prepared to tailor their information accordingly. Young people may also need more emotional support throughout the testing process. Research has shown that adolescents are significantly less likely to return for their result and post-test counseling than adults,³ and a counselor who establishes a strong therapeutic bond during pre-test counseling can not only make the process easier but also increase the likelihood of return.

For many young people at risk, the test site counseling session is their only opportunity to have an open discussion about HIV and other health concerns. Such counseling

information about the client are obtained, offers greater protection of a young person's identity, which can be very important, especially for those who may mistrust the "system." On the other hand, confidential testing, especially in the context of an existing counseling or support program, offers more opportunities for direct linkages to needed services following the result, especially if it is positive.

Counseling on HIV issues need not be limited to sites that conduct testing. Health and social service providers in a wide range of clinical or educational settings can integrate HIV awareness into their counseling with young people and can successfully link them to test sites and subsequent services.⁴

In the coming months and years, advances in the science of HIV testing and care may profoundly affect not only the way young people learn their HIV status, but also the options available to them should they test positive. Some of the most significant developments include:

Promising new anti-retrovirals. A new category of anti-retroviral drugs, protease inhibitors, have shown dramatic ability to suppress viral activity when used in combination with existing drugs. Recent research suggests that the weeks following infection are crucial to the natural history of HIV disease, as rampant viral activity seeds tissues throughout the body, and that anti-retroviral therapy during this period may be able to forestall long-term damage.⁵ In that case, accessibility of testing services so that people can learn their status following a risky encounter is crucial.

On the other hand, the long-term benefits of protease inhibitors are unknown. Furthermore, compliance with a multi-drug regimen is very burdensome, involving more than a dozen pills a day, and there are serious adverse consequences of skipping doses or taking "drug holidays."⁶ For many young people, especially those at highest risk, who may be dealing with substance use, low self-esteem, or life on the streets, such compliance is unrealistic.

Advances in testing technology. At least one major HIV clinic, Whitman Walker in Washington, D.C., has announced it will begin using oral fluid collected on swabs for its HIV testing instead of blood.⁷ This method, which detects antibodies not in saliva but in a fluid secreted by the mucosa that line the mouth, is as accurate as the blood test,⁸ and may make

For a testing controversy, press 1

With the approval last year of two home collection kits, a new world of HIV testing opened up — to the applause of some and the dismay of many.

Direct Access Diagnostics received FDA approval to market its kit, Confide, in May 1996, and Home Access/Home Access Express received clearance in July 1996. Both are home *collection* kits, through which a user draws a blood sample and sends it to a laboratory for testing; they are not actual home *tests* that provide the result immediately.

Both kits are available by mail-order directly from the companies, as well as in some pharmacies. Both contain: a booklet with information about HIV/AIDS,

instructions for performing the test, a lancet to gather a blood sample from a finger, the sample collection card, a return envelope to send in the test, and an anonymous code number. Users send the blood sample to a laboratory which screens for the antibodies to HIV using the ELISA test, and if necessary, a confirmatory Western Blot test. These are the same tests used by clinics that do HIV testing.

The results for Confide and Home Access are available in one week, while Home Access Express results are available in three days.

The cost of Confide in the pharmacy is \$40, and by
(continued on next page)

testing much more accessible by taking it out of clinical settings. Oral testing offers new possibilities for reaching street-involved youth and other populations less likely to go into a clinic.

In addition, sophisticated viral tests such as the PCR, which can detect HIV within a matter of hours or days, may eliminate the six-month “window period” of infection. Although these tests are not widely used to detect HIV, they may become more widespread, requiring new guidelines for counseling.

Home collection kits. Perhaps no development in HIV testing has stirred as much controversy as the approval of home test kits. Many youth and their advocates have voiced concerns about confidentiality, the possibility of coercion, and the lack of face-to-face counseling. The accompanying articles examine this complex issue.

Epidemiological evidence shows that rates of HIV infection continue at alarming rates in adolescents and young adults. Approximately one in four new HIV infections in the U.S. is estimated

to occur in someone age 22 or younger.⁹ Without widely available, youth-sensitive testing initiatives, many of these youth will remain unaware of their status and unable to access life-enhancing care, both medical and psychosocial. In addition, many more youth who are not infected but engaging in high-risk behaviors may lack an opportunity to receive risk reduction counseling through the testing process.

Given these realities, providers should take a “pro-choice” stand on testing, and give young people the information they need to make their own decision. The challenge to providers — not only those who work in HIV testing sites, but also those in a position to encourage testing by youth — is to support young people in making appropriate decisions; to provide thorough, non-judgmental risk assessment and counseling; to protect confidentiality; and to be prepared to link young people to needed services, especially in the event of a positive result. With this kind of support, HIV testing can be an important step in a young person’s growth and development.

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mail-order \$49; it is also being offered through college health centers and clinics for \$30-35. Home Access costs \$39.95, and Home Access Express is \$44.99. (These are the listed prices; the actual price may vary at your local pharmacy.)

A primary argument in favor of home testing is expanding access to testing for at-risk populations who might not otherwise learn their status. A report in the *New England Journal of Medicine* noted that 29% of respondents to the 1992 National Health Interview Survey said they would be likely to use home HIV tests. Of subjects who were determined to be at risk for HIV infection, 42% stated they would be "very" or "somewhat" likely to use an at-home test. Of that group, 63% had never been tested. The sample comprised subjects 18 and older; in the 18-24 year old group, 44% stated they would be "very" or "somewhat" likely to use home testing. Other groups that were more likely to use the test were African Americans, Latinos, and respondents with lower incomes and lower educational levels.

These results are compelling because they indicate possible increased use of testing in difficult-to-reach segments of the population. However, the survey did not discuss what the cost of the test might be; given the current prices, those who might be most interested in using one of the kits may find the cost prohibitive. Still, these data give an idea of groups who might be responsive to home tests.

Most of the opposition to home collection kits have centered around the adequacy of counseling. For both kits, those receiving a negative result hear only a recorded message (with the option of

speaking to an operator). Opponents have also questioned the ability of telephone counselors to support those receiving a positive result, and have raised concerns about the accuracy and appropriateness of referrals that may be provided.

Possible use of the tests by adolescents and young adults has been especially controversial. Currently, there are no age restrictions on the purchase of home kits. Although the box states that the test is "recommended for persons 18 and over," anyone who can afford a kit can buy one. Whether or not youth use the tests, and how they are served by the telephone counselors, will be a crucial area to assess.

In addition, many advocates for youth have expressed concern about possible coercion of youth by parents, guardians or older adults. While the kit materials clearly state that the tests should only be used on a voluntary basis, the potential for this type of abuse is easy to imagine, and will be another important area to follow.

Home collection kits may be a valuable way for more people to become aware of their HIV status. However, because they have only been available for a short time, it is too early to know whether or not they are being used by the groups that might benefit the most from them, and whether the counseling and support they provide are adequate. Providers who work with young people should continue to build trusting relationships and give youth information and support as they consider the HIV test. Indeed, this support may be more important than ever if more youth turn to home collection kits in lieu of confidential or anonymous testing through a clinical setting.

Are HIV home collection kits "youth-friendly"? What's the packaging like? How is the counseling? To get the consumer perspective, Bridges asked two young people to describe their experience using home kits.  **Heather Lusk, 25, is a training coordinator for HIFY's Training and Resource Center. She first tested when she was 19 and tested negative again most recently in January of this year. Stefan Milenkovic, 24, a member of HIFY's Youth Services Team, first tested positive when he was 15. Their stories and their opinions are on pages 5-6.**  **While the accuracy of an HIV test is fairly easy to evaluate objectively, the effectiveness of counseling and education is more open to subjective judgments. The psycho-social realm will be an important focus for evaluation as home test kits become more widely used, and youth voices such as the ones offered here should be a key part of that evaluation.**

"Your result is negative..."

HEATHER: Advertisements for HIV home tests depicted them as an easy way to find out the answer to a difficult and scary question. I was intrigued yet skeptical about taking my HIV test at home. I also wondered how the procedure would affect me as a young person.

The test kits are both excessively packaged, resulting in a two-foot-long spread of booklets, blood sample supplies, and return envelopes. I was feeling a tad overwhelmed, and appreciated Home Access' inclusion of a handy checklist/diagram of the kit's contents (especially for folks like me who had no idea what a lancet is). I was encouraged by both products' bilingual Spanish/English instructions but discouraged by the separation of the test instruction and HIV/AIDS information. Realistically, how many youth would take the time to read the separate HIV/AIDS booklet as I did? Neither book is particularly inviting in its vague and dry language. The text is cautious, non-youth-friendly and without pictures. I was particularly perplexed by Confide's very broad definition of HIV risk behaviors, and pondered how puzzled I would be if this was my first introduction to HIV/AIDS information.

The instructions for both testing procedures were concise and pretty easy to comprehend. The tests' selling point of convenience is right on ... they supply you with everything you could ever need, from bandages to disposal containers to postage-paid return packages. I was ready to bleed. Gathering my blood sample was relatively painless, and soon I was bandaged and my blood was on its way to the lab. Home Access required me to register prior to sending my sample; I answered a short automated survey (age, who I have sex with, prior HIV tests, etc.). I felt reassured that my future results counselor would have some basic background information while maintaining my anonymity. Now I just had to wait.

The morning my results were available, (one week for Confide, three days for Home Access Express) I closed the door, took some deep breaths, and made the call to Confide. Initially, I was asked by an automated system to answer a survey very similar to the demographic questions I had answered before sending in my Home Access test. Despite my eagerness, I took the time to answer the questions, guessing their response rate would be pretty low considering the anxious period in which they are requesting information. When it was finally time to hear my results, an automated voice droned "Your test results are negative...this means you do not have HIV...unless you've been infected in the last six months." My entire

(continued on next page)

"Your result is positive..."

STEFAN: I was originally tested for HIV in 1987 in England. At that time I was 15 years old, HIV worldwide was but five years of age and was still very much the "gay plague." When I was given my result by phone I was very surprised to find that it was positive. I received no in-depth post test counseling and feel that the whole experience was a little — well — depressing. Things changed soon thereafter though; it became illegal in England to give results of this nature over the telephone. Nine years later when I was asked to write about the new home kits, I jumped on the opportunity.

Upon opening the boxes, I found that the two tests vary only slightly. The information included in them both seemed to be aimed at a heterosexual of above-average comprehension and education, but the instructions for the Confide test were more graphical and more easily explained the procedures involved. However, the Home Access test requires that you call in and answer demographic information at the time of drawing blood. That somehow made the experience much more tangible for some reason. Generally I feel that the information was of a high enough quality but was not designed for use by a young person.

The testing procedure is something I found very difficult and do not think it is something a young person could safely and privately achieve in all circumstances. The process of stabbing yourself with a lancet, squeezing blood into little circles, ensuring that the blood passes to the back of the card, etc. seems more than a little macabre. Further I feel that the lancets included for drawing blood should be returned to the manufacturer either for recycling or disposal. These items, along with the rest of the packaging for that matter, are not things a parent would relish finding in the trash and could cause any number of questions to be asked.

Getting my results from Confide went like this.

"Do you have your 14 digit access code?"

"01747905040785"

"I have to tell you that your test result came back positive for the HIV antibody, this means you have the HIV virus, HIV is the virus that causes AIDS, HIV and AIDS are not the same thing. What did you expect your result to be?"

"...."

We got past the initial terror of the diagnosis and the resultant shocked silence very quickly. Ruth, our friendly operator, who incidentally hadn't asked for my name,

(continued on next page)



HEATHER (FROM PREVIOUS PAGE)

pre- and post-test experience with Confide was completely automated (with an extremely vague definition of the window period). I listened as the recording went on in a monotone, basically reading verbatim the HIV/AIDS booklet included in the kit, for ten minutes before I had the opportunity to speak to a live counselor.

I should have stayed with the computer. My "counselor" was impersonal and vague as well. She didn't ask any clarifying questions to assess my age, needs, risks or knowledge. I also discovered she had no access to my previous survey answers, nor any awareness of the information I was forced to listen to before I had the opportunity to speak with her. I felt confused about her generic explanations to my questions, especially when she gave me wrong information. This traumatic counseling session ended with another plug for using Confide for my follow-up test since "only confidential testing is available in your area." Knowing this to be false, I pressed for a referral in San Francisco for anonymous testing. She gave me a number for the Department of Public Health, which (surprise) was a wrong number.

My experience with Home Access also began with a recorded voice telling me my results are negative. Unlike Confide, however, I received a clear and concise definition of the window period, as well as an opportunity to speak to a live counselor within seconds of receiving my result. A major difference was that my counselor had my survey answers in front of her, so she knew I was a young adult, knew I had a prior negative HIV test, and had an idea of my risk behaviors. Overall, I felt much more comfortable with this counselor, and she provided an overview of the continuum of risk behaviors, as well as more direct answers to questions I asked. Her plug for Home Access in my follow-up testing was a little inappropriate, but her referral to the SF AIDS Foundation Hotline was much more helpful than any assistance I received from Confide.

My experience with Confide was appalling and I am nervous and scared when I think of other young people believing it is a safe and easy way to find out their HIV status. While Home Access was the lesser of two evils, I am hesitant to promote its use without an accompanying counseling session from an outside source. Obviously home testing does not have the intervention quality that confidential and even anonymous testing may have on reducing the risk for HIV transmission. I'm not as concerned about that fact as I am about the possibility of a young person finding out their result in such an impersonal and potentially destructive manner.

STEFAN (FROM PREVIOUS PAGE)

began to read what sounded like a scripted counseling session. She was going to refer me to an appropriate agency as soon as possible whether I liked it or not. "The database," she told me, would like me to go to the Immune Enhancement Project for my primary care, as well as alternative therapies. (The Immune Enhancement Project does not provide primary care.) When I pointed out that I was a young person she referred me to the Balboa High Teen Clinic. I was uncomfortable with these referrals so she finally referred me to the Cole Street Youth Clinic. I feel that more appropriate referrals would have been possible had she more accurate information, but still feel that she would not have the knowledge of services a local test clinic would have. The conversation finished with Ruth telling me that it seemed to her that I wanted to get off the phone.

Julie was my operator for the Home Access result. She had a much calmer manner and seemed to be willing to spend the time for me to process the way I was feeling before she launched into a counseling session. She passed on my result quite compassionately and made three referrals to local AIDS agencies. Again, these referrals were inaccurate, most notably that SF AIDS Foundation would provide me with primary health care.

When I tried to become maudlin about the information I had just received, she pointed out there were these 'neat' new drugs which prolong people's lives now and that people don't get AIDS for ten years anyhow. I pushed the ten year AIDS prognosis to a degree by suggesting that because I am a young person that means I couldn't possibly have been infected long ago; therefore I wouldn't get sick soon. I was hoping that she would pick up on my age and suggest that I could have been infected as soon as I had my first sexual contact. Instead she told me that ten years was a good estimate and that lots of people get sick earlier.

My general view about both kits was that the counselors did not have enough information about the virus, progression, the 'neat new drugs' protease inhibitors or local services. More to the point, it is not possible for these people to have this local information unless they are to spend time working in the communities which they aim to profit from. The operators did not even attempt to ascertain my mental state prior to giving me the result. Neither of them determined that I was a young person, addressed issues such as testing for other STD's and hepatitis, vaccination against other diseases, or asked why I had initially decided to take the test.

The views expressed here represent the opinions of the authors.

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FEATURE TOPIC

Adolescents and HIV

This is the first of two articles that will discuss the practice of HIV/AIDS counseling and treatment of adolescents. This article provides an overview of the epidemic among youth and outlines the central psychosocial issues as well as methods for counseling, prevention, and outreach. The second article — to appear in March — will examine clinical care of HIV-infected adolescents.

Worldwide, the highest rate of new HIV infections is among young people. Half of the 5.8 million new infections in the past year occurred among youth between the ages of 15 and 24.¹ In the U.S., 25% of new infections occur in persons aged 13 to 21 years: a rate of one new infection every hour.²

*Worldwide, the highest
rate of new HIV infections
is among young people.*

RISK FOR HIV INFECTION AND SEXUALLY TRANSMITTED DISEASES

In 1996, the Institute of Medicine released a report that highlights the interaction of behavioral, biological, and socioeconomic factors that increase the vulnerability of adolescents (particularly females) to sexually transmitted diseases (STDs), including HIV infection. Sexually transmitted diseases are known to increase susceptibility to HIV. Of the 12 million cases of STDs reported in the U.S. each year, 25% occur among teenagers and 2/3 are acquired by the age of 25. Forty-six percent of reported cases of chlamydia — the most common STD in the U.S. — occur in female adolescents aged 15 to 19 years.³

Behavioral Factors

Many normative behaviors of adolescents intersect with risk-taking behaviors. Sexual activity is often initiated during adolescence; 48% of high school youth report sexual intercourse, with 16% having engaged in sexual intercourse with more than four partners. Only 50% of youth report condom use at last intercourse.⁴ Youth who are gay, bisexual, transgender, homeless or runaway, injection drug users, incarcerated, in foster care, mentally ill, or have been sexually or physically abused are at increased risk for HIV infection because of greater exposure to the virus in their social networks. These vulnerable adolescents also experience higher rates of health and social problems in general than do other youth.

Experimentation with alcohol and other drugs is common during adolescence and is associated with an increase in risk-taking activities, including sexual activity and violence. Alcohol and drug use may also impede the development of psychosocial skills. Adolescents are less likely than adults to recognize their drug or alcohol use as problematic. Rarely do they initiate drug treatment on their own. Instead they tend to enter treatment systems through their schools, parents, or the criminal justice system. One-third of high school youth⁵ report drinking five or more alcoholic beverages at least once in the prior month, more than 25% smoke marijuana, and 16% report use of inhalants such as industrial solvents, paints, and nitrates. Heroin use among teens has nearly doubled since 1991, and nearly 1 in 50 high school students report having injected an illegal drug.⁶

Biological Factors

Several biological risk factors contribute to the heightened infection rate among young women, including: 1) the physical developmental stage of the cervix — during puberty the single-layer columnar cells (known to be more susceptible to chla-

mydia and the gonococcus) are replaced by less susceptible multilayer squamous cells, 2) the greater efficiency of STD transmission from males to females because of the mechanics of sexual intercourse and the larger surface area of the female genital tract, and 3) the fact that sexually transmitted diseases are more likely to be asymptomatic (thus remaining unnoticed and untreated) for a longer period of time in women.

Socioeconomic Factors

Poverty and lack of access to health care, education, and prevention tools are associated with increased vulnerability to HIV. Twenty-five percent of youths aged 15 to 29 years have no health insurance. Youth face additional barriers to receiving adequate care. Many adolescents fear inappropriate disclosure or do not understand their right to confidentiality in the provider-client relationship. They often use walk-in facilities and hospital emergency rooms for their acute health care needs and so do not build a relationship with a health care provider. Moreover, providers often are unable to communicate risk reduction messages adequately. Since adolescence is a time when behavior patterns, cognitive skills, decision-making ability, and attitudes towards health and self care are established, youths' experiences with health care providers form the basis for future provider-client relationships, communication patterns, and help-seeking behaviors.¹⁰

State laws allow minors to consent to treatment (without parental consent) for specific health services, including emergency care, STDs, and substance abuse treatment services; but not all providers are aware of these rights.⁷ As long as explicit information and messages remain controversial, the lack of adequate sex education for youth will continue to result in new HIV infections. Supportive and direct safe sex education for gay and bisexual youth is even more constrained, denying health-enhancing information to this vulnerable population. Moreover, the adolescents who are at greatest risk are those most likely to be outside systems that could provide prevention, counseling, testing, and treatment services.

EPIDEMIOLOGY OF HIV INFECTION IN YOUTH

International and national studies demonstrate that the AIDS pandemic remains dynamic among adolescents. Nineteen percent of U.S. AIDS cases occur among people in their 20s.⁸ It is estimated that one in four new infections strike people by age 21, and this may be lower than the actual rate because of the 10-year latency period between HIV infection and the development of AIDS.

In comparison to adults, a disproportionate number of African-American and Hispanic adolescents are HIV positive, accounting for 59% of the AIDS cases in this age group in the U.S. From 1988 to 1993, estimates of HIV prevalence increased 36% among women aged 18 to 22 while declining 27% among men in the same age group.⁹ In 1997, females comprised 37% of AIDS cases among adolescents aged 13 to 19 compared with 18% among adult AIDS cases. The majority of young women with AIDS (52%) are infected in heterosexual encounters, with an additional 15% to 20% presumed to be infected sexually but classified as having "no identified risk" because they are unable to name their partner's risk factor. Injection drug use accounts for a much smaller percentage of transmission in this population than among adult women (13% of 13- to 19-year-olds and 27% of 20- to 24-year-olds). Perinatally infected youth account for a small but growing number of adolescents living with HIV/AIDS.

The leading transmission category among adolescent males remains receipt of infected blood products (before 1985) by youth with hemophilia and other coagulation disorders, accounting for 43% of male teen AIDS cases. The next highest transmission group in young males is male-sex-with-males, accounting for 33% of cumulative transmission in teens and 62% in males aged 20 to 24. However, by 1996 male-sex-with-males had become the leading transmission category for new infections among teenage boys. There is a difference between behavior and sexual orientation that is important to keep in mind in communicating with young people. Same-sex experimentation is more common than the development of a gay or bisexual identity. Moreover, for gay or bisexual youth,

identity development is a process that unfolds over several years. Some youth infected in same-sex encounters do not identify as gay or bisexual, and for this reason, safe-sex messages directed at gays may not be viewed as personally relevant.¹⁰

YOUTH OF HIV+ PARENTS

It is estimated that by the year 2000, over 80,000 U.S. children and teenagers will have lost a parent to AIDS. In addition to the emotional devastation of this loss, the great disruption that occurs in families where a parent is ill or dies may heighten risk behaviors among youth. Children of HIV+ parents are also often living in communities with high rates of HIV, placing them at increased risk of infection. The percentage of children of HIV+ parents who are themselves infected is unknown. However, a review of 81 sexually infected teens followed at Montefiore Medical Center's Adolescent AIDS Program¹¹ found that 21% reported having at least one HIV+ parent. The ways in which parental HIV infection mediates sexual risk behaviors and subsequent HIV infection in youth needs further research. However, these findings are already guiding a program initiative to offer risk assessment, referrals for care, and HIV counseling and testing to the adolescent children of patients followed in Montefiore's Adult AIDS Program.

ADOLESCENT-SPECIFIC HIV COUNSELING, TESTING, AND PREVENTION

Although many youth engaging in unsafe practices do not believe that they are at risk, it is a myth that adolescents do not get tested for HIV and do not want providers to ask personal questions. In fact, many youth prefer that the clinician initiate such discussions.¹² The promise of new advances in HIV care, combined with the documented advantages of early detection, heightens the need for routine HIV counseling and testing among youth in more settings than just prenatal care.

In order to be successful, HIV-testing programs must be accessible to youth. Mobile units, school-based health clinics, and drug treatment programs are venues particularly well situated to provide testing programs geared to young people. Services need to be youth-friendly, flexible, free or low cost, and help youth overcome barriers such as transportation. In states with mandatory

partner notification laws, providers may need to discuss with adolescents the implications of the law and the availability of anonymous HIV testing. However, the confidential testing relationship establishes a stronger clinical bond, opportunity for follow-up, and youth-sensitive care, compared with anonymous testing.

The pretest counseling visit presents an opportunity for the health provider to promote preventive health behaviors and assess concerns such as substance use or family planning needs. It also provides an invaluable opportunity to educate adolescents about condom use and safer sex, regardless of whether testing occurs. Effective HIV counseling for adolescents should be culturally sensitive and tailored to the developmental needs of the youth and in accordance with local laws (see Table 1). Youth who are judged to

be at risk for self-destructive or impulsive behaviors require careful assessment prior to testing. Special care to safeguard confidentiality should be taken in settings such as foster care, residential institutions, or detention facilities.¹³

There are new options for HIV testing that have not been extensively implemented with adolescents. For example, OraSure, a noninvasive test that collects an oral sample, can facilitate testing in nonmedical settings. Rapid HIV tests enable youth to learn their HIV antibody status on the day they are tested, with a negative test being definitive and a positive test requiring further confirmation. While this method potentially increases the number of youth who learn their antibody status, implementation of rapid HIV testing will necessitate changes in how and when prevention

counseling is delivered to youth. Regardless of the testing method, a "one shot" approach to counseling does not work with all at-risk youth. Two short counseling sessions using personalized risk reduction plans can increase condom use and prevent new HIV and other STD infections.¹⁴ Funding is needed to support more than one counseling session for some at-risk adolescents.

All facilities providing adolescent medical care should make condoms available and provide education on their proper use. Among the reasons youth have difficulty incorporating condoms into their sex lives are 1) lack of knowledge on effective use, 2) lack of communication and social skills, 3) lack of availability of condoms at the time of sexual

(Continued on page 15)

Table 1. Teen AIDER (Assess, Inquire, Discuss, Educate, Readiness) Interview

I. ASSESS AND INQUIRE

CREATE A CONFIDENTIAL ATMOSPHERE

- Assure youth that visit is confidential, that testing is their choice, and that they are free to consent to or decline testing per local laws
- Acknowledge that it can be embarrassing to discuss sexual behaviors
- Help youth to identify a supportive adult who is aware that he/she is being tested

HIV/AIDS KNOWLEDGE

- Allow adolescent to verbalize understanding of HIV. Clarify misconceptions and fill in knowledge gaps
- Assess youth's feelings about testing and previous HIV testing experiences
- Inquire if youth knows anyone with HIV/AIDS (e.g., sexual partner, family member)

SEXUAL RISK ASSESSMENT

- Assess sexual behaviors without making assumptions about sexual orientation
- Assess number of partners, age differential, and their known risks
- Assess frequency of substance use in the context of sexual behavior
- Assess consistency of condom use and obstacles to use (e.g., unassertiveness, desire to become pregnant, fear of violence, or religious beliefs)
- Assess for history of sexual abuse or rape

SUBSTANCE USE AND OTHER RISK ASSESSMENT

- Assess level of drug and alcohol use and contexts in which use occurs
- Review risk of impaired judgment that may result in unsafe sex
- Assess potential need and motivation for drug treatment
- Assess violence and substance use in home and community

II. DISCUSS AND EDUCATE

- Discuss postponing sex for youth who are not sexually active
- Demonstrate proper male condom, female condom, and dental dam use on anatomical model, and provide opportunity for practice
- Discuss sexual activities that do not involve exchange of body fluids (outercourse)
- Rehearse effective ways to communicate risk reduction with sexual partner(s)
- Discuss harm reduction strategies for youth using drugs
- Develop a personalized risk-reduction plan

III. READINESS FOR HIV TESTING AND REFERRAL

- Inform adolescent about both anonymous and confidential testing
- Provide education about partner notification programs and other options for disclosure to partners
- Assess youth's understanding of the meanings of positive and negative test results
- Assess youth's understanding of benefits of early intervention
- Determine with youth if testing should occur at this time and, if so, obtain informed consent
- Discuss strategies for coping (how to relieve stress and anxiety during the testing process)
- Arrange follow-up appointment and means of contacting youth confidentially, if needed
- Determine referral needs (e.g., medical, psychosocial, school/vocational, substance abuse, reproductive health, legal, housing, psychiatric)

tutes as PCP prophylaxis for those who cannot tolerate TMP/SMX. While the toxicities for both drugs were comparable, study authors found that atovaquone was easier to tolerate than dapsone in dapsone-naïve patients. Further research is needed into alternatives for PCP prophylaxis in TMP/SMX-intolerant patients.

El-Sadr WM et al. Atovaquone compared with dapsone for the prevention of *Pneumocystis carinii* pneumonia in patients with HIV infection who cannot tolerate trimethoprim, sulfonamides, or both. *N Engl J Med* 1998 Dec 24; 339:1889-95.

Prophylaxis Against Fungal Infections

Fluconazole administered weekly was roughly equivalent to daily administration in preventing invasive fungal disease and slightly less efficacious in preventing thrush. Itraconazole is effective in preventing relapse of *Penicillium marneffei*.

In patients with HIV, fungal infections cause a broad spectrum of diseases, presenting everything from mild complications to life-threatening conditions. Two recent studies looked at the efficacy of fungal prophylaxis. The first studied the use of fluconazole. Fluconazole is effective in preventing thrush, but it is not routinely employed as prophylaxis against candida and cryptococcus strains because it has not been shown to reduce mortality, is expen-

sive, and may lead to wider emergence of azole-resistant fungi, which are difficult to treat. This study explored whether weekly dosage of fluconazole is as efficacious, less expensive, and less likely to lead to resistance as compared with daily use.

Researchers compared fluconazole 400 mg weekly with 200 mg daily in a randomized, double-blind trial of 636 HIV-infected persons, all of whom had CD4 counts below 100 cells/mm³. Invasive fungal disease (candidal esophagitis, candidemia, cryptococcosis, or histoplasmosis) occurred in 5.5% of daily users and 7.7% of weekly users. Mucocutaneous candidiasis occurred in 12.3% of daily users and 19.9% of weekly users. There was no important difference in the rates of fluconazole-resistant isolates. Only 2 of 26 isolates analyzed were resistant to fluconazole.

Weekly fluconazole did not offer major benefits over daily fluconazole and was slightly less efficacious in preventing superficial disease. This and other studies indicate that the routine use of fluconazole in the primary prevention of fungal disease is not warranted. Fluconazole may be useful in patients with particularly severe and frequent recurrences of disease.

The second study looked at the administration of itraconazole to prevent relapse after an episode of *Penicillium marneffei*. *P. marneffei* is a common cause of invasive fungal disease in Southeast Asia, Hong Kong, and southern China. In Thailand, it is the third most common opportunistic infection after tuberculosis and cryptococcosis.

Researchers enrolled 72 HIV+ Thai patients who had completed initial therapy for *P. marneffei*. Patients were randomly assigned to receive itraconazole 200 mg daily or placebo. The mean CD4 count was 71 cells/mm³ in the itraconazole group and 65 cells/mm³ in the placebo group. None of the patients were receiving antiretroviral therapy. Twenty of 35 patients in the placebo group suffered a relapse of *P. marneffei* after a median interval of 24 weeks. No patient in the itraconazole group relapsed. The study was not designed to detect a mortality difference, and none was noted. Mortality ranged from 31% to 43% at 48 weeks in this advanced population.

Whether or not secondary prophylaxis against invasive fungal disease should be continued indefinitely, even after prolonged and successful viral suppression with HAART, remains unclear. For the time being, it seems prudent to continue prophylaxis against cryptococcosis, histoplasmosis, and *P. marneffei* until the issue is resolved through clinical trials.

Havlic et al. Prophylaxis with weekly versus daily fluconazole for fungal infections in patients with AIDS. *Clin Infect Dis* Dec 1998; 27:1369-75.

Supparatpinyo K et al. A controlled trial of itraconazole to prevent relapse of *Penicillium marneffei* infection with patients infected with HIV. *N Engl J Med* 1998 Dec 10; 339:1739-43.

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FEATURE TOPIC

(Continued from page 11)

activity, and 4) impulsive behavior exacerbated by drug or alcohol use. Because condoms are used by men, gender power imbalances in relationships (heightened when the male partner is older) contribute to the greater vulnerability of adolescent females and gay males. Helping youth to identify their personal values may increase self-esteem and help them resist pressures to engage in risky sexual behaviors.

When assessing potential referral sources, health care providers should note that successful primary and secondary programs for adolescents are those that increase self-esteem and self efficacy, build social skills, and provide basic information. Successful prevention programs (not primary and secondary

programs) are often built on a peer support model, and use adolescents to promote and diffuse the skills they learn into the community at large. Ideally, broad-based education and skills building to motivate the formulation of healthy patterns of behavior should occur before youth become sexually active.

OUTREACH

Community outreach is central to the care of HIV+ youth. It is essential to engage the attention of youth at risk for HIV and their health care providers concerning the need for and availability of services for prevention and care. The majority of HIV-infected youth are unaware of their infection, and connections with community service agencies are necessary to link adolescents with age-appropriate services that address

their considerable mental health and social service needs.

Recognizing that existing agencies have not been sufficient to identify at-risk and HIV+ youth and link them to care, the Adolescent AIDS Program initiated a social marketing campaign spanning the HIV continuum, from prevention to testing to care. "HIV. Live with it. Get Tested." uses youth language for having sex ("knockin' boots" or "hittin' the skins") and links HIV risk with the importance of HIV testing. Designed in collaboration with an ad agency, medical communications company, and adolescents themselves, the campaign used media placements and community outreach in the venues of at-risk youth to promote testing and care services at a

(Continued on back page)

(Continued from page 15)

New York City-wide coalition of adolescent HIV programs and community-based youth agencies. A highly successful component of the campaign was "Get Tested! Week," launched at a youth-led town hall meeting. The campaign generated extensive media coverage, more than 2,000 calls to the hot line, and — when coupled with peer-led community outreach — increased testing.¹⁵ The initial success of this campaign has prompted efforts to duplicate it on a national level within the Adolescent Medicine HIV/AIDS Research Network (AMHARN).¹⁶

CONCLUSION

HIV infection in adolescents continues to challenge health care providers, policy makers, and advocates for youth. Primary care providers working with at-risk youth and their parents are in a unique position to identify or help develop HIV prevention and care programs that address multiple needs. Effective interventions are those that move beyond moralism to realism and show a willingness to engage young people. Youth at high risk for HIV should be identified and engaged in primary care as soon as possible. HIV+ youth need intensive individual and group interventions to stay healthy and reduce transmission to others. It is incumbent on all providers to make adolescent services visible, flexible, affordable, confidential, culturally appropriate, and available for all youth.

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HIV Counseling, Testing, and Prevention

Although adolescents are at increasing risk for HIV infection, relatively few have access to HIV counseling and testing. Until recently, publicly funded programs have not targeted adolescents, and many providers are not comfortable offering HIV testing to youth, fearing that they will not be able to handle positive results. Existing counseling and testing programs are not generally accessible to young people, who often do not know where to go for testing and may not be able to pay for such services. This is beginning to change as the impact of the AIDS epidemic on the nation's youth finally is being acknowledged.

The report to President Clinton on adolescent AIDS calls for making counseling and testing programs accessible to adolescents, including developing CDC guidelines addressing the special needs of youth in counseling and testing services (CTS).¹⁵ Moreover, a policy statement from the AIDS Policy Center for Children, Youth and Families calls for all health care programs to review existing policies and to ensure that providers are trained in the developmental needs of youth.¹ Until these services are more widespread, however, adolescents who are sexually active and who use injection drugs remain unidentified and unserved. Providing routine counseling about HIV and offering voluntary testing are critical elements of early intervention, risk assessment, and client education. Guidelines are available to assist providers in incorporating HIV testing into routine adolescent primary care.¹² In addition, specific guidelines are included in this chapter, and a comprehensive protocol is provided in Appendix E.

Goals and Principles of HIV Counseling and Testing (Table 13.1)

Like other underserved populations, many adolescents generally are diagnosed late in the course of illness when intervention with emerging treatment strategies may be less effective.¹⁹ Relatively few currently receive care for HIV disease, and most do not know they are infected. For example, nearly half of adolescents seen at an adolescent AIDS clinic showed significant immune dysfunction at the time of their initial visit.⁶ With few options for case finding, including limited availability of counseling and testing services, adolescents are medically disadvantaged, and their HIV prevention and care needs are neglected and often ignored.

The development of new anti-viral drugs for treating HIV infection offers promising treatment possibilities through combination therapy and use of protease inhibitors, a new class of drugs that significantly reduce the amount of HIV in the body and that have been shown to prolong life and decrease AIDS-related disorders. To be most effective, however, providers must be able to monitor levels of HIV (viral load) to determine disease progression and make decisions about when to intervene. Without knowledge of HIV status and access to HIV-related care, these options are not possible.

The primary goal of offering HIV counseling and testing to adolescents is to identify HIV-positive youth, to provide ongoing medical care and support services,

TABLE 13.1. Benefits of HIV Counseling and Testing for Adolescents

Identify HIV+ adolescents and provide medical and support services
Relieve anxiety for HIV-negative adolescents
Discuss sexual orientation, behaviors, and practices
Provide risk assessment and identify high-risk behaviors
Provide HIV education, risk reduction information, and skills training
Provide appropriate referrals for non-HIV-related care and support services, if HIV negative (e.g., alcohol and drug treatment, counseling)

and to relieve anxiety for youth who are HIV-negative. Counseling and testing also offer other benefits for risk reduction, prevention, and ancillary care. During pre- and post-test counseling, providers have an opportunity to talk about sexual behaviors and orientation, to identify high-risk behaviors and practices that may not have been acknowledged or discussed previously, to develop an individualized risk-reduction plan, and to refer adolescents for other health problems such as alcohol and drug treatment and mental health services.

Lack of generalized training for providers about HIV counseling and testing and poor integration of CTS services into primary care (most counseling and testing services have been offered either at separate sites or provided in conjunction with STD clinics) have contributed to the perception among many providers that counseling and testing require specialized skills and abilities and are difficult to include as a part of routine patient care. Although an understanding of the principles and goals of counseling and testing is important, providers can readily incorporate HIV counseling and testing into routine assessment and care by following the guidelines included in Appendix E and by familiarizing themselves with related state laws.

Studies have shown that health care providers play an important role in helping teens to identify risk behaviors and to make decisions about HIV testing. A survey of Boston-area high school students found that most adolescents want physicians to ask personal questions about HIV-related risk behaviors and prefer that providers initiate this discussion.¹⁶ After receiving routine counseling with the option of HIV testing from primary care providers, a significant proportion of high-risk adolescent girls chose to be tested.⁸ Provider initiation is essential because many high-risk youth may not acknowledge risk behaviors. For example, more than three-quarters of adolescents tested in Houston public health programs over a 2-year period denied having any risk behaviors, including nearly half (49%) of all youth who tested positive for HIV.¹⁰

Principles of HIV Counseling and Testing (Table 13.2)

HIV counseling and testing should be voluntary and should include specific informed consent. Clinicians have found that most adolescents are capable of understanding the risks and benefits of medical treatment and thus can give informed consent.¹⁴ Moreover, a comprehensive analysis of research on adolescent decision-making shows that adolescents, particularly those aged 14 years and over, have the capacity to make their own health care decisions.⁷ Because the decision to take an HIV test is anxiety-provoking and has a significant impact on the lives of youth who are found to be positive, providers should help to identify a supportive adult who can be involved in the testing process. The adult may be a parent, teacher, counselor, or older friend.

Providers should carefully explain the benefits of HIV testing and potential impact of disclosure, including discrimination, on persons who are known to be HIV-

TABLE 13.2. Principles of HIV Counseling and Testing with Adolescents

HIV counseling and testing should be voluntary and should include specific informed consent.
All sexually active adolescents should be offered HIV testing; however, testing should not be coercive. Providers should carefully explain the benefits of HIV testing, discuss confidentiality, potential discrimination, and disclosure requirements (if any), based on state law.
Providers should help the youth to identify a supportive adult to be involved in the testing process and to provide ongoing assistance and support.
Information on HIV testing, prevention, and follow-up care should be presented in clear, culturally, linguistically, and developmentally appropriate language.
Adolescents should be informed clearly that they continue to receive ongoing care, whether or not they choose to be tested. Some adolescents may need several sessions to talk about their concerns before making a decision about testing.
Special care should be taken to protect confidentiality in residential programs, institutional settings, detention facilities, and foster care.
HIV counseling and testing should be made available and accessible to adolescents. This includes offering CTS during evening hours, providing CTS in settings in which adolescents routinely receive care, and offering anonymous as well as confidential testing (with strong linkages to follow-up care if testing is anonymous).
Providers who recommend HIV testing should assist and follow-up actively after making the referral (if counseling and testing are not on-site).
Providers should develop a practical, achievable risk-reduction plan with adolescents who are HIV-negative; although risk reduction is also a goal for HIV-positive youth, the primary goal of post-test counseling is emotional stabilization, medical referral, and psychosocial follow-up.
All pregnant adolescents with HIV should receive information about the benefits and potential risks of anti-retroviral use during pregnancy to reduce perinatal transmission of HIV, based on HRSA implementation guidelines. ⁴⁷ This information should include age-appropriate discussion, inclusion of family members in decision-making, and adequate time to discuss concerns.

infected. Confidentiality should be clearly delineated; in some states, test results may be disclosed to others upon request. Providers should ensure that adolescents are not coerced and do not perceive that their health care will be jeopardized if they refuse to be tested. If testing does not occur on site, providers should make the referral and follow-up personally to ensure that results are received and that needs are addressed. All settings where youth are referred for care, including CTS sites, should be assessed for sensitivity to adolescent needs, policies related to HIV testing, capacity to provide comprehensive care, and linkages to care in other settings. Agencies that serve adolescents also should ensure that primary care and CTS services are accessible. This may include providing services at times that do not conflict with school or work, ensuring that services are located near public transportation, and addressing financial barriers.

Legal Issues

Adolescents aged 18 years or older are considered adults legally in almost all states and can thus consent to treatment. Those under 18 years of age are considered to be minors, and although parental consent generally is required for health care, all states have laws that allow minors to consent to diagnosis and treatment of STDs.⁵ However, not all states have classified HIV as an STD or a venereal disease (classifications that permit adolescents to consent to treatment under these statutes). Most states have also enacted laws enabling minors to consent to treatment for other health concerns, including mental health, alcohol and drug problems, rape, sexual assault, and pregnancy.

By the mid-1980s, states had enacted a broad range of HIV-related laws, the largest portion of which dealt with HIV testing. Approximately 32 states allow minors to consent to HIV testing and treatment.² In other states, minors may be able to consent under laws that cover specific services, such as those for STDs, contagious or communicable diseases, pregnancy, or family planning, or under laws that authorize minors' consent on the basis of their status.⁵

In addition to consent to testing laws and existing confidentiality laws that cover HIV, some states, including Delaware, Florida, and Iowa, have passed legislation that restricts adolescent testing or treatment information from disclosure.² In particular, Delaware and Florida's laws prohibit health care providers from indirectly divulging confidential information through such practices as sending a bill for services to a minor's home or to a person other than the minor.² Laws in three states allow disclosure of HIV testing and treatment to a minor's parent or legal guardian. Colorado allows disclosure for unemancipated minors or those under age 16; Michigan allows disclosure when the minor's parent or legal guardian requests written disclosure; and Iowa requires minors to be informed before testing that HIV-positive results will be disclosed to their parents or legal guardians.

Providing HIV Counseling and Testing for Adolescents

Recent treatment advances with combination therapy and protease inhibitors call for proactive case finding and outreach efforts to identify and initiate treatment for HIV-positive adolescents. However, access to care requires wider access to age-appropriate counseling and testing services, and greater commitment among providers to counsel and routinely offer HIV testing with informed consent to all sexually active adolescents.

Providers should counsel all sexually active adolescents about the need for HIV testing and offer voluntary testing with informed consent. Providers should help youth determine appropriate timing for the test. Some teens may choose to be tested when the option is offered; others may need more time to talk about it or may choose to defer testing to a less stressful time (e.g., after exams). This section includes an outline for providing HIV counseling and testing in primary care settings. (See Appendix E for complete guidelines.)

Pre-Test Counseling (see Table 13.8)

When discussing the need for HIV testing, providers should explain the increasing prevalence of HIV infection in adolescents, especially the high prevalence among young gay males. They should help youth personalize risk and discuss how specific sexual or drug-using behaviors have put them at risk for HIV infection. Testing should never be coercive. Adolescents should be informed clearly that they will continue to receive ongoing care, whether or not they choose to be tested. Information should be presented in clear, culturally, linguistically, and developmentally appropriate language. Providers can assess an adolescent's developmental level by considering how youth respond to the following during the counseling session: (a) thought process (concrete vs. abstract), (b) future orientation, (c) ability to plan, (d) capacity to weigh options, (e) ability to assess risk realistically, and (f) ability to assess skills for implementing behavioral change.¹²

If an adolescent is considering the test, providers should help identify a supportive adult to be involved in the testing process and to provide ongoing assistance and

support; this adult should be someone on whom the youth can rely and with whom he or she has a trusting relationship (e.g., parent, teacher, counselor).

RISK ASSESSMENT AND HIV EDUCATION (Tables 13.3–13.5)

If an adolescent has not been seen before, providers should conduct a risk assessment and review previous test history. The assessment includes determining risk for transmission through sexual behavior, needle sharing, blood products, and perinatal transmission. It also includes a sexual and substance use history, including use of drugs and alcohol during sexual intercourse (*see* Appendix E).

Whether test results are positive or negative, HIV counseling offers an opportunity for identifying risk behaviors, fostering communication and interaction skills, and developing strategies for minimizing risk. Providers should determine an adolescent's knowledge of HIV transmission and AIDS; many youth have misconceptions about how HIV is transmitted (*see* Table 13.3). Ask the adolescent to explain what he or she knows, and fill in the gaps. Discuss the risks of various behaviors: unprotected anal, vaginal, and oral sex; use of alcohol and drugs during sex; and needle sharing. If an adolescent is not sexually active, counseling provides an opportunity to talk about sexual readiness, delaying intercourse, and ways to increase intimacy other than risky sexual behaviors.

Even if an adolescent does not acknowledge engaging in specific behaviors, providers should review all risk behaviors, carefully distinguishing between low-risk and high-risk activities. Some adolescents, particularly those who may be lesbian or gay, are reluctant to ask questions about safer sex or condom use, fearing negative or judgmental reactions. Providers should demonstrate condom use, preferably with an anatomic model, and explain use of the female condom, as well as dental dams for oral-anal and oral-vaginal sex. Asking questions about the difficulties teens routinely experience when using condoms may help to identify specific barriers (e.g., if condoms break, providers can discuss proper use and recommend nonoxynol 9 for lubrication).

Providers should help youth to strategize ways to reduce risk, with the interim goal of reducing harm or minimization of risk for HIV infection. For example, many teens are unaware that alcohol and drug use before and during sex can affect judgment and increase risk for HIV. Experimentation with alcohol and marijuana is common among adolescents. Expecting them to abstain entirely is unrealistic for most; however, getting them to agree not to use alcohol or drugs during or immediately before sex is

TABLE 13.3. Basic Concepts for Explaining HIV to Adolescents

The HIV antibody test is a test for HIV infection, not AIDS.

An antibody is like a "footprint" indicating that someone has been exposed to HIV.

People may carry the virus in their bodies for many years before developing HIV-related symptoms or AIDS.

HIV affects the ability of the immune system to function properly.

New drugs are intended to prevent the virus from reproducing in the body to keep the immune system working for as long as possible.

Continuing to practice unsafe sex or needle sharing can cause reinfection, which may make HIV disease worse and cause symptoms to appear sooner.

Practicing safer sex and not sharing needles are essential to protect one's health and one's partner's health.

Partners also should be tested for HIV infection.

TABLE 13.4. Elements of a Sexual Risk History

1. How old were you when you first had sexual intercourse (oral, vaginal, or anal)? How old was your partner?
2. Do you consider yourself heterosexual, gay or lesbian, or bisexual? Or are you unsure?
3. Do you have sex with men, women, or both?
4. Tell me about your sexual experiences: how often have you had oral, vaginal, or anal sex? How many partners have you had? Did you give or receive oral, vaginal, or anal sex (insertive or receptive)? What percentage of the time did you use condoms? Tell me about your sexual experiences during the past month.
5. Tell me about the number of partners you have had. How old were they? Did any have risk factors for HIV infection? (Did they use injection drugs? Did they have multiple partners? Were they gay or bisexual?)
6. Have you ever had an STD? (Provider should describe symptoms of common STDs.) Tell me what kinds you may have had or what the symptoms may have been. Did you receive treatment? What kind?
7. What kinds of birth control have you used? Have you ever tried to prevent STDs? If so, how?
8. Have you ever been pregnant, had a baby, had an abortion or miscarriage?
9. Have you ever used drugs or alcohol before or during sex?
10. Have you ever had sex in exchange for food, money, drugs, or a place to live or sleep?
11. Has anyone ever forced you to have sex or do something sexually that you did not want to do?
12. Do you have any questions or concerns about your current sexual experiences?
13. What do you know about "safer sex"? Are you doing anything to protect yourself and your partners from being infected with HIV? How do you feel about changing your sexual behavior to prevent HIV infection or reinfection? What sexual behavior will you miss? How does your partner feel about safer sex? Does your partner know that you have HIV? Do you need help telling your partner?
14. Do you think condoms can prevent HIV and STDs? If you do, what makes it hard to use condoms? Did you use a condom the last time you had intercourse? Why or why not? What would make it easier for you to use condoms?

From Kunins H, Hein K, Futterman D, et al: Guide to adolescent HIV/AIDS program development. J Adolesc Health 14:1S, 1993, with permission.

a more practical and achievable goal. Likewise, youth who inject drugs may not be ready to enter a treatment program. While continuing to offer substance abuse treatment, providers can help minimize risk by showing teens who use injection drugs how to clean equipment, encouraging them to teach their needle-sharing friends and strongly recommending not sharing needles. In addition, providers should caution adolescents to avoid sharing ear-piercing and tattooing equipment.

Risk education should culminate with the development of an individualized risk-reduction plan. As with other tasks that require negotiation and communication skills, providers may assist adolescents by asking concrete questions, planning specific responses, and conducting role plays to enhance self-efficacy and increase confidence.

CONFIDENTIALITY AND DISCLOSURE

Providers should explain the benefits of HIV testing (e.g., risk reduction, early intervention), and discuss confidentiality of test results, including disclosure requirements (if any) based on state law, as well as potential negative reactions of others when positive results are disclosed (discrimination and stigma). Adolescents should understand the difference between anonymous and confidential testing.* Although confi-

*Providers should be aware that some adolescents may ask for anonymous testing because they falsely assume that being "anonymous" will prevent others from learning their HIV status. Their motivation for seeking anonymous testing is based on concrete thinking, and not on an accurate understanding of the actual difference between anonymous and confidential testing. If they are HIV+, their care will be confidential, not anonymous.

TABLE 13.5. Elements of a Drug Use History

1. Do you, any of your friends, or your sexual partners ever use any of these drugs: alcohol, marijuana, crack, cocaine, heroin, amphetamines, hallucinogens (LSD, PCP), barbiturates, sedatives, or steroids? Do you take any of them at the same time? Which ones?
2. For each drug you use, tell me about how old you were when you started using it, how often you have used it during the past month, how often you use it each day, and the ways you use it (pills, snorting, sniffing, injection).
3. Where do you use drugs? Alone, with friends, lovers, at parties? Where do you buy drugs (friends, the street, crack houses, shooting galleries)?
4. If you have injected drugs, tell me about your needle use. How often do you share needles and with whom; how do you clean them; how often do you use works in a shooting gallery?
5. If you smoke crack, tell me about your crack use. How often do you use crack? What percentage of the time do you use in crack houses? How often do you have sex in crack houses, and what types of sex do you have?
6. Have you ever exchanged sex for drugs?
7. How do you get money to buy drugs?
8. Have you ever had medical problems because of drug use (visited a doctor or hospital), overdosed, or tried to hurt or kill yourself because of drugs?
9. Have you ever been in trouble with the law or had problems with your family, school, or work because of drugs?
10. Do you think you are addicted or have a problem with drugs, including alcohol?
11. Have you ever tried to get off drugs or tried to stop drinking? How have you tried? What kinds of treatment programs have you tried?

From Kunins H, Hein K, Futterman D, et al: Guide to adolescent HIV/AIDS program development. *J Adolesc Health* 14:1S, 1993, with permission.

dential testing is preferred because linkages to care are ensured more effectively, anonymous testing may be more appropriate for some youth, particularly when concerns about disclosure are paramount. If anonymous testing is warranted, providers should make arrangements for the test, which include addressing transportation needs, and follow-up after testing to ensure that results have been received and that care and support needs are addressed.

HIV ANTIBODY TEST

Providers should (1) explain the long latency period between infection and symptoms and explain how HIV affects the immune system; (2) describe how the antibody test works and what it may indicate if a person is negative or positive; and (3) explain the "window period" and why retesting is necessary within 6 months if someone has recently been exposed to HIV.

Use of the terms "positive" and "negative" to indicate test results may be confusing for teens because they understand the opposite meanings in everyday use; i.e., positive connotes good and negative means bad. Adolescents must understand clearly that a positive result means they have been exposed to HIV and have been infected. Not everyone who tests positive to the antibody test has or develops AIDS. People may carry the virus in their bodies for many years before developing HIV-related symptoms or AIDS. Describing how HIV works on the immune system helps adolescents to understand why early intervention is important and helps to underscore the need for avoiding reinfection. Providers should raise the issue of partner notification during the pretest session. Adolescents generally are uncomfortable talking about partner notification; nevertheless, this issue should be addressed with them.

follow-up sessions, with providers offering to help if an adolescent feels he or she is unable to do so. Providers might explain the need for notifying partners by saying: "If you test positive for HIV, it is important to let your sexual or needle-sharing partners know so that they can find out if they are infected, get counseling and care, and protect themselves and others from infection. They can decide whether or not to get tested."¹²

NEW HIV TESTING OPTIONS

Providers should be aware of new testing developments that expand options for HIV testing (Table 13.6). The developments include same-day testing (rapid assay), non-serum-based testing (urine and oral fluids), and home collection kits. Although providers may prefer drawing blood on site and following routine testing procedures, they may encounter youth who have used a home collection kit and require appropriate counseling and followup, or they may choose new testing options to maximize flexibility in various settings, such as outreach programs or situations in which immediate results are needed.

TABLE 13.6. Expanded HIV Testing Options

Type of Test	Sensitivity*	Specificity†	Results	Procedure
Home collection system				
• Confide	100%	99.95%	7 days	Test kit includes pretest counseling and blood collection items; user pricks finger, drops blood sample on enclosed test card and mails to the lab in a preaddressed envelope. No identifying information is required; results are obtained by calling the counseling center and giving the test identification number supplied with the kit. Positive results are retested twice, with a confirmatory Western blot. Counseling is provided by phone with local referral information.
• Home Access	100%	100%	3–7 days	
Oral fluid test				
• OraSure	99.5%	99.5%	3 days	Oral fluids are collected on a cotton pad placed in the mouth for 2–5 minutes (test available only through a physician). Specimen is sent to the lab; positive results are retested and confirmed with an oral Western blot test. Results are given by provider.
Rapid serum test				
• Single-use	99.9%	99.6%	10 minutes	Blood is drawn and mixed with reagent in a test tube; within 10 minutes, a potentially positive result changes color. Test can be used to confirm HIV-negative status, but positive results require follow-up with a standard HIV test to confirm HIV infection. Results are given by provider.
Urine test				
• Sentinel	98.7%	99.1%	2.5 hours	Urine specimen is mixed with reagent; a potentially positive result changes color. Test can be used to confirm HIV-negative status, but positive results require follow-up with a standard HIV test to confirm HIV infection. Results are given by provider.

* Ability to accurately identify HIV-infected persons.

† Ability to screen out uninfected persons.

Adapted from Massachusetts Medical Society: Novel approaches to HIV antibody testing. *AIDS Clinical Care* 9:1, 1997.

With the exception of the home collection system, through which testing is controlled by the individual, other testing options must be administered in the presence of a health care provider. However, the shorter turn-around time for results and the ability to avoid drawing blood (e.g., oral fluids and urine tests) increase their utility and appeal. In addition, most tests have acceptable and, in some cases, excellent sensitivity (ability to accurately identify HIV-infected persons) and specificity (ability to screen out uninfected persons).^{1a} With adolescents who are extremely anxious, the ability to reduce waiting time and confirm negative results makes these tests the preferred option.

ADVANTAGES AND DISADVANTAGES OF HIV TESTING

Providers should help adolescents explore the benefits and potential drawbacks of learning their HIV status (Table 13.7). They might introduce the topic by asking: "What do you think are the benefits of knowing your HIV-positive status?" In addition to responses the youth may give, the benefits include (1) providing an opportunity for early intervention and enhancing quality of life; (2) avoiding reinfection or other STDs; (3) enabling youth to develop positive self-care and coping skills and to adjust to living with HIV before receiving an AIDS diagnosis; (4) providing important information for family planning decisions; and (5) protecting others from infection.

A similar question should be asked about disadvantages: "What are some of the drawbacks of knowing you are HIV-positive?" The drawbacks include (1) negative reactions from family and friends; (2) discrimination and stigma if others find out; (3) intense emotional distress and feelings of wanting to harm oneself or others; (4) difficulty getting or paying for care; and (5) fears about dying.

The goals of this discussion are to help adolescents understand the significance of being tested and the potential implications if they are infected and to help providers learn more about each adolescent's ability to handle the results.

COPING SKILLS—MANAGING RESULTS

Understanding more about how adolescents cope with other major life events may provide key information about how they may respond to positive HIV results and what kinds of support may be needed. Providers might ask: "Have you ever had to deal with difficult situations or really upsetting news in the past? How did you (might you) handle something like that?" Responses that youth provide should be applied to

TABLE 13.7. Advantages and Disadvantages of Anonymous vs. Confidential HIV Testing

Type of Testing	Advantages	Disadvantages
Anonymous testing	Blood samples are labeled with an identifying number; the person's name is not used. No one but the test recipient gets the results, so negative reactions are avoided.	Anonymous testing makes it more difficult to provide followup care because providers do not know a person's test result. Services for HIV+ adolescents are limited and are more difficult to assess without the support of a knowledgeable provider.
Confidential testing	Testing can be provided by the primary care provider so that followup care, support, and advocacy can be delivered. Adolescents can receive care from a provider with whom they have an ongoing relationship.	In states with disclosure laws, results may be shared with parents or other agencies. Even under the best of circumstances, confidential information may sometimes be disclosed inadvertently or accidentally.

TABLE 13.8. Protocol for HIV Pre-Test Counseling with Adolescents

Provide HIV counseling for all adolescents.

Offer HIV testing to all sexually active adolescents with informed consent.

Testing should not be coercive.

- Clearly inform youth they they will continue to receive ongoing care, whether or not they choose to be tested.
- Help youth to identify a supportive adult to be involved in the testing process and to provide ongoing assistance and support; identify support system.
- Review previous test history, if any.

Risk assessment

1. Discuss risk in the context of an adolescent's sexual, drug-use, or other risk behaviors.
2. For new clients, conduct risk assessment.
 - a. Sexual behavior and condom use
 - b. Alcohol, drug, and needle use
 - c. Blood products
 - d. Perinatal transmission

HIV/AIDS knowledge

1. Discuss adolescent's knowledge of HIV transmission and course of disease
 - a. Routes of transmission
 - b. Difference between HIV and AIDS
 - c. Latency period and effect on immune system

Risk reduction education

1. Provide risk reduction education.
 - a. Discuss readiness for sexual activity (if not yet sexually active).
 - Recommend delaying sex.
 - Discuss ways to increase intimacy without having sex.
2. Discuss safer sex and demonstrate protection methods.
 - a. Condoms
 - b. Dental dams
 - c. Female condoms
3. Discuss strategies for partner negotiation.
 - a. Role play and talk about appropriate responses
4. Discuss safer needle use.
 - a. Harm reduction (talk about cleaning injection equipment)
 - b. Needle exchange programs
 - c. Avoid sharing tattoo and ear-piercing equipment
5. Discuss use of alcohol and drugs during sex.
 - a. Develop strategies to minimize risk.

Testing issues

1. Explain differences between anonymous and confidential testing.
2. Explain meaning of test results.
 - a. Antibody response following infection
 - b. Negative, positive, indeterminate
3. Explain the pros and cons of HIV testing.
4. Discuss confidentiality, potential discrimination and stigma, and disclosure requirements (if any), based on state law.
5. Obtain consent.
6. Draw blood.
7. Answer questions and discuss coping strategies until results are available.
8. Schedule appointment for test results (in person).

Follow-up and referral

Adapted from Chabon B, Futterman D, Jones C: Adolescent HIV Counseling and Testing Protocol, Adolescent AIDS Program, Montefiore Medical Center, 1995.

how they may deal with waiting for/coping with their test results. Providers should help teens to anticipate their results and imagine what their responses may be by asking: "If you decide to get tested, what do you think your results might be?"

Using a role play to explore feelings about being positive (or negative) helps an adolescent get in touch with his or her feelings and helps providers determine the youth's capacity to handle test results and the level of support he or she may require initially. Providers may introduce the role play by saying:

I'd like you to pretend that you have decided to take the HIV test. Let's pretend that it is 2 weeks from today, and you have come back to get your test results. Can you imagine what that would feel like? Close your eyes if it makes it easier to imagine.

You are going to get your test results today. You have come to see me, and I ask you to sit down. I tell you that your results are positive. How would you feel? What would you say or do?¹²

Continue to role play for a few minutes while the youth describes his or her reactions. Role play giving a negative test result, and use the session to talk about the "window period" and the need for possible retesting if the youth has recently been exposed to HIV. This is a good opportunity to reinforce the need for avoiding risky behavior in the future.

Using this information, providers need to let the adolescent know how long he or she will have to wait to get results, to talk about how he or she expects to cope during that time, and to identify sources of support if they require it. The provider might ask:

How do you think you are going to feel while you are waiting for your test results?

Can you talk about being tested with anyone? If so, with whom, and what would you tell him or her?

What can you do if you feel really upset or nervous?¹²

If an adolescent has no additional support, the provider should identify an interim referral and provide contact information during the waiting period (in some cases, the waiting period for routine HIV testing may take 2 weeks or longer).

CONSENT FOR HIV TESTING

The provider and adolescent should determine whether the adolescent is ready for testing. Some youth may lack adequate support or appear emotionally unready. If so, testing should be delayed until he or she is ready. If the adolescent decides to be tested, he or she should read and sign an appropriate consent form that meets legal and institutional standards.

The provider should answer any additional questions, reinforce plans for coping during the waiting period, provide contact numbers, and encourage the youth to call with questions or concerns in the interim. Schedule a followup appointment to provide test results, which are not given over the phone, and let the youth know that he or she will be contacted if he or she fails to return for results.

Post-Test Counseling (Table 13.9)

The components of post-test counseling for adolescents are similar, whether results are negative, positive, or indeterminate. When informing adolescents of test results, providers should be straightforward, give results at the beginning of the session, and allow adequate time for the youth to respond. The session should include risk reduc-

TABLE 13.9. Protocol for HIV Post-Test Counseling with Adolescents

Post-Test Counseling for HIV+ Adolescents

- Provide results and answer questions.
- Allow youth time to respond.
- Encourage expression of feelings; anticipate traumatic reaction (may include denial, panic, crying, anger, fear, self-blame, relief).
- After youth has adequately expressed feelings, reflect back their response.
 - Explore fears (fear of dying is common).
- Assess potential for suicide and need for immediate mental health intervention.
- Explain meaning of positive test results.
 - Exposure/infection with HIV
 - Describe difference between HIV and AIDS.
- Explain that people with HIV can live active productive lives for many years.
 - Remind youth of treatment options.
- Discuss support system.
 - Explore who they can tell about their HIV positive status.
 - Caution about inappropriate disclosure (e.g., potential discrimination).
 - Provide information about what to do if they experience discrimination.
 - Offer to assist with disclosure, if necessary (e.g., meeting with parents).
- Assess immediate needs (e.g., housing, safety) and develop plans to address them.
- Review routes of transmission and prevention (blood, semen, tissue, organs, razors, toothbrushes, breastfeeding, needle-sharing).
- Reinforce risk reduction strategies.
 - Practice safer sex and condom use.
 - Avoid sharing needles or works.
 - Clean needles before use.
 - Seek drug treatment referral, if appropriate
 - Partner negotiation/disclosure
- Discuss strategies for partner notification.
- If adolescent is pregnant, provide information on the benefits and potential risks of antiretroviral use during pregnancy to reduce perinatal transmission of HIV. Provide additional counseling to the adolescent and family/support system to assist in decision-making; include adequate time to discuss concerns.
- Establish support plan for next 48 hours and longer term (next week).
- Make followup appointment for medical care and provide contact information.
 - 24-hour crisis hotline
 - Emergency mental health care
- Ensure emotional stability before session ends.

Post-Test Counseling for HIV-Negative Adolescents

- Provide results and answer questions.
- Allow youth time to respond.
- Encourage expression of feelings.
- Explain meaning of negative test results.
 - No evidence of exposure/infection with HIV
 - Not necessarily free of HIV ("window" period)
 - Need to be retested if engaged in risky behavior within past 6 months
- Review and reinforce risk reduction strategies.
 - Practice safer sex and condom use.
 - Avoid sharing needles or works.
 - Clean needles before use.
 - Seek drug treatment referral, if appropriate.
 - Partner negotiation/disclosure
- Address additional questions.
- Assess need for additional referrals and make appointments (e.g., health and social services, mental health services, etc.).
- Provide health education literature.

Adapted from Chabon B, Futterman D, Jones C: Adolescent HIV Counseling and Testing Protocol, Adolescent AIDS Program, Montefiore Medical Center, 1995.

tion counseling, reinforce negotiation skills, and identify additional referral needs. Before the session ends, providers should make required appointments for followup services with other agencies. Predictably, counseling HIV-positive adolescents requires additional time to express and acknowledge feelings, identify immediate needs, assess for suicide potential, and develop a plan for coping and mobilizing support.

POST-TEST COUNSELING FOR HIV+ ADOLESCENTS

Provide Results. Providers should give results directly without engaging in casual conversation and wait for the youth to respond. A forthright approach is best: "Your test results show that you are HIV-positive, which means that you have HIV infection."

Encourage and Validate Response. An immediate response to others' distress is to try to comfort them. However, providers should allow the adolescent time to react; this may require sitting in silence while the youth absorbs the information. If the adolescent does not react directly, giving him or her permission to express feelings is often helpful: "You must be having a lot of feelings right now. It might be helpful to sort them out. Which one feels most intense?"

Common reactions include denial, panic, crying, anger, fear, guilt and self-blame, and even relief. After the adolescent has expressed immediate reactions, acknowledge his or her feelings and help interpret test results. A common though often unexpressed concern is fear of dying. Understanding that HIV infection is a chronic infection, not a "death sentence," may help motivate development of appropriate self-care and health utilization skills. For example, a provider might say:

HIV infection is a chronic illness that requires medical care and support. Many people with HIV live active, productive lives for many years. HIV is not a death sentence. New treatments can help your body fight HIV and resist infections. Over time, HIV slowly weakens the body's ability to fight infection. That is why it is really important to get a lot of support and learn how to take care of yourself. You need to learn how to reduce stress, prevent reinfection with HIV, and get proper medical care. We need to take this one step at a time.

Establish Counseling Goals. In addition to helping youth to label and express their feelings about being HIV-positive, goals of post-test counseling with HIV+ adolescents include (1) ensuring that adolescents understand that HIV infection is a treatable, chronic illness; (2) helping identify and mobilize the adolescent's support system; (3) reinforcing risk-reduction messages and skills, including the need for partner notification; (4) assessing immediate mental health needs and suicide potential; and (5) developing short- and long-term plans for continued care and follow-up.

Identify Support System. Adolescents need help to identify and mobilize their support system. This includes (1) identifying persons in their lives who provide ongoing emotional and financial support; (2) discussing potential reactions to their HIV status, including discrimination and rejection; (3) determining persons with whom they can safely share their HIV test results; and (4) developing a plan for informing appropriate persons. If a supportive adult has participated in the post-test session, he or she can assist with notifying key persons in the youth's support system.

Inform Key Persons. Many youth express concerns about confidentiality and feel overwhelmed by the prospect of having to inform their parents and notify partners. Providers can offer to help by scheduling a meeting with the adolescent and his or her family, and by assisting with partner notification through role play or a face-to-face meeting.

Reinforce Risk Reduction Behaviors. As with pre-test counseling, providers should reinforce the need for risk reduction and review strategies, such as using condoms and dental dams; cleaning and not sharing needles; avoiding alcohol and drugs before or during sex; and negotiating risk reduction with partners to avoid risky behaviors.

Develop Response Plan. In addition to addressing needs for immediate support, providers should help the adolescent develop an immediate and long-term plan for managing emotional and health-related needs. This includes coping with test results, managing fears and feelings, and asking for help when they need it. Providers may prompt discussion by asking several basic questions:

What do you think you need to do next?

What will you do when you leave here today?

Let's talk about some other options.

Is _____ someone you might be able to talk with?

What can you do if you are alone and feel scared or overwhelmed?¹²

Referral and Follow-up. After scheduling a followup medical appointment, providers should give the youth a list of contact persons, including phone numbers for a 24-hour crisis line and emergency mental health services. Providers should develop a specific plan for addressing traumatic reactions following receipt of test results: the adolescent should be encouraged to call the provider with specific concerns before the next appointment; if the youth feels suicidal or extremely anxious, he or she should immediately call the crisis hotline or emergency mental health services.

Before the session ends, providers should assess the adolescent's level of emotional stability. If additional emotional support is needed, the provider should make an immediate referral for mental health services.

POST-TEST COUNSELING FOR HIV-NEGATIVE ADOLESCENTS

Providers should follow the protocol for post-test counseling with HIV-negative adolescents (*see* previous pages and Appendix H). The goals of counseling with HIV-negative youth include (1) determining whether a followup test is needed (youth who have engaged in risky behavior within the past 6 months should be retested within 6 months); (2) reinforcing risk-reduction messages and skills; and (3) developing an individualized risk-reduction plan that will be reassessed during subsequent primary care visits. A negative test result provides an important opportunity for reinforcing low-risk behaviors. However, adolescents who have engaged in high-risk acts within the past 6 months are not necessarily HIV-negative. Providers should carefully explain the "window" period during which antibodies routinely develop and should reschedule a follow-up test within the next 6 months.

Prevention (Tables 13.10 and 13.11)

A common argument against educating adolescents about sex is that providing information encourages them to become sexually active. In fact, the opposite is true. A comprehensive review of 23 school-based programs designed to reduce risky sexual behaviors found that teens who received AIDS education were actually less likely to engage in sex and more likely to practice safer sex than peers who did not.¹¹

Without an effective vaccine, prevention remains the most important strategy for reducing the spread of HIV infection. Promoting risk reduction with adolescents is

TABLE 13.10. Developmental Characteristics that Increase Adolescents' Risk for HIV Infection

Perceptions of invulnerability	Concrete rather than abstract thinking
Present time orientation and impulsivity	Reliance on peer approval
Denial of danger	Fatalistic attitudes among many high-risk teens

particularly challenging because developmental characteristics foster concrete, short-term thinking, encourage experimentation and risk-taking, and increase reliance on peers. Behavioral interventions have been successful in reducing short-term risk, although long-term changes are much more difficult to maintain.²² For example, a study of responses to an HIV-prevention program for gay and bisexual males showed significant reduction in the number of unprotected, same-sex anal and oral sex activities.²¹ Youth maintained reduced risk through a 12-month follow-up, although frequency increased over a 2-year period.²⁰ Abstinence was significantly more likely among younger adolescents and those who had not been sexually active prior to the intervention; even with prevention intervention, however, gay and bisexual adolescents who engaged in commercial sex increased their sexual risk behaviors. In another study evaluating a similar intervention among mid-western gay and bisexual youth, 60% showed a decrease in unprotected anal sex during follow-up, including more consistent use of condoms.¹⁷ Findings underscore the need for early intervention (before age 13), for anticipating relapse and for consistent reinforcement of prevention messages by providers.

Predictors of unsafe sex for gay and bisexual youth have been identified; these include high levels of anxiety and depression, frequent alcohol use,²⁰ substance abuse,¹⁸ lack of communication with partners about risk reduction, having a steady partner, and having frequent intercourse.¹⁸ Among the limited, nonrepresentative studies of gay male adolescents, three risk patterns have been identified: (1) young gay males are more likely than older gay men to engage in risky sexual behavior; (2) reported substance use is high and linked to risky sexual behavior; and (3) some young gay males barter sex, use condoms infrequently, and have multiple male partners, generally older adult males.²⁰ Although similar data are not available for lesbian adolescents, reported frequency of heterosexual activity, sex with gay male peers, and inconsistent condom use puts them at high risk for HIV infection. These data emphasize the need to provide support for lesbian and gay adolescents to build self-esteem and enhance self-care behaviors, particularly when youth are struggling with issues related to coming out.

PROMOTING RISK REDUCTION AND PREVENTION

Knowledge of the basic principles and goals for risk reduction can help providers respond most effectively to adolescents' behavioral learning needs (Table 13.12). Even highly motivated adults have difficulty maintaining healthy behaviors consistently.

TABLE 13.11. Factors that Promote Successful Risk Reduction for Adolescents

Capacity to personalize risk and belief that one's actions can make a difference
Knowledge and opportunity to practice risk-reduction skills
Perception that peer group supports risk-reduction behaviors
Opportunity to experience repeated messages to reinforce health-promoting behaviors

TABLE 13.12. Principles for Promoting Positive Behavioral Change in Adolescents

Help adolescents to personalize their risk and believe that their actions can make a difference.
Develop individualized risk reduction goals based on each adolescent's needs: Help to identify a range of options for behavioral change.
Clarify the difference between high- and low-risk behaviors; demonstrate condom use.
Set realistic behavioral goals that focus on minimizing risk rather than eliminating it entirely.
Build communication, decision-making, and assertiveness skills, through role playing and interactive exercises, to enable adolescents to resist negative peer pressure and to negotiate safer sex and safer drug use.
Encourage youth to delay sexual activity and to protect themselves if they become sexually active.
Identify and discuss values and beliefs (family, adolescent, and peers).
Address cultural attitudes about sexuality and condom use.
Include sexual orientation and behavior in discussions with all adolescents.
Consistently repeat risk-reduction messages and reinforce health-promoting behaviors.

Expecting adolescents to comply with difficult, awkward, or embarrassing behavior changes without implementation skills sets them up to fail. Teaching adolescents how to reduce risk for HIV before they initiate sex or drug use is much more effective than trying to change established behaviors. Because adolescents are developmentally inclined toward risk-taking and sensation-seeking and because peer pressure is often extreme, providers should encourage youth to delay sexual activity and, at the same time, teach them how to protect themselves. "Don't drink, but if you do, don't drive is a comparable prevention paradigm.

Providers must also recognize that change is incremental and that behaviors are best modified by setting realistic goals. This requires a thorough risk assessment and development of an individualized risk-reduction plan. Lesbian and gay adolescents may feel overwhelmed by the severity of the AIDS epidemic within the gay community. Providers can help them understand that change is possible by discussing the remarkable changes that have occurred in gay male sexual behavior during the 1980s described as the most profound behavioral change ever occurring in public health.⁴ In order to develop and sustain health-promoting behavior, adolescents must believe that they have the ability to practice and/or change their behaviors. This includes demonstrating condom use and engaging in role playing and interactive exercises to help build communication, decision-making, and assertiveness skills.

Unlike other life-threatening diseases that develop over a period of years, resulting from poor diet, smoking, or a sedentary lifestyle, HIV can be contracted through a single episode of risky behavior. Thus, HIV prevention and risk assessment are no longer optional elements of care, but must be included as a routine part of primary care for all adolescents.

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Appendix E

Adolescent HIV Counseling and Testing Protocol*

PRE-TEST COUNSELING

I. Introduction

- Review previous test history, if any.
- Clearly inform youth they will continue to receive ongoing care, whether or not they choose to be tested.
- Help youth to identify a supportive adult to be involved in the testing process and to provide ongoing assistance and support.

II. HIV/AIDS Knowledge

- Routes of transmission
- Affect of HIV on the immune system

III. Risk Assessment

- Sexual risk assessment
- Drug use assessment
- Blood products
- Maternal transmission

IV. Risk Reduction Education

- Decision making and readiness for sexual experience
- Safer sex
 - Condom demonstration
 - Dental dam
 - Female condom
- Safer needle use
- Sex and drugs

V. Testing Issues

- Types of testing
 - Anonymous
 - Confidential
- Meaning of HIV test results
 - Positive
 - Negative
 - Indeterminate
- Pros and cons of HIV testing
- Obtaining consent

VI. Issues for Followup and Referral

- Managing results
 - Coping strategies
 - Partner notification
- Medical
- Psychosocial
- School-related
- Other

* Adapted from Brenda Chabon, PhD, Donna Futterman, MD, Colleen Jones, FNP: Adolescent HIV Counseling and Testing Protocol, Adolescent AIDS Program, Montefiore Medical Center, 1995.

This protocol is intended for use by providers in primary care settings who have ongoing relationships with adolescents and their families. Some of the assessment information requested here may already have been obtained during routine provision of care. If a provider has already conducted a thorough risk assessment for HIV with an adolescent, the protocol should be adapted accordingly.

Pre-Test Counseling Session

I. Introduction

- Begin session and review reasons for testing.

Allow the adolescent to verbalize his or her understanding of HIV and why he or she seeks testing, or explain why you have recommended testing. Encourage the youth to express feelings about being tested. Assure the youth that care will not be adversely affected should he or she decide not to be tested. Testing should not be coercive. When medical indications call for immediate testing, the provider should explain the need for testing, help the adolescent to deal with potential resistance, and follow the protocol for counseling and obtaining informed consent.

Help to identify a supportive adult (parent, counselor) who can be involved in the testing process.

- Do you know anyone who is HIV+ or has AIDS? (ask youth to identify all that apply)
 - Parent
 - Friend
 - Sexual partner
 - Relative
 - Drug using partner
 - Other _____

- Review testing history: Have you ever been tested for HIV before?

This is particularly relevant for new clients; however, some adolescents may have been tested before without telling anyone. Asking about previous HIV-testing experiences helps to assess counseling and support needs.

- Why? _____
- How many times? _____
- Where? _____
- When? ____/____/____
- Did you go back for the results?
____ Yes
____ No (Why not?)
- If yes, what were the results?
 - Positive
 - Negative
 - Don't Know

II. HIV Knowledge

A. Routes of transmission

Ask the adolescent to identify routes of transmission for HIV. Fill in knowledge gaps, clarify misconceptions, and add risk behaviors not mentioned.

- Can you tell me how people get infected with HIV?

Ask questions to evaluate adolescent's level of understanding for each mode of transmission:

- Sexual transmission
- Needle sharing/body piercing
- Blood product transfusion before 1985
- Maternal/child transmission
- Tattooing
- Not spread through casual contact

- HIV is present in blood, semen, "pre-cum" (pre-ejaculatory fluid), vaginal fluids, and breast milk.
- HIV is minimally present in saliva but is very dilute, with no known cases of transmission from kissing.
- HIV is not spread through casual contact (e.g., public toilets, touching, sharing cigarettes).
- Medical and mental health care can help to prevent life-threatening infections and help people to cope with having HIV.

B. How HIV Acts on the Immune System**11. What do you know about HIV and AIDS?**

Ask the adolescent to describe what happens when someone gets infected with HIV, how the immune system responds, and how HIV affects the immune system. Ask him or her to explain the difference between HIV and AIDS and what he or she knows about the course of disease.

Include the following concepts:

- HIV does not equal AIDS, and not all persons with HIV infection have AIDS.
- Average latency period (HIV progression to symptoms of AIDS) is 10 years.
- HIV suppresses the immune system, leaving the body unable to fight certain diseases.
- Teens with HIV infection can be very healthy for a long time—attend school, get a job, have productive, active lives. Care and medication help teens with HIV live healthier lives.
- Antibodies take a while to develop, generally 3–6 months before the HIV test is able to detect them ("window period"). That is why some people who were recently exposed to HIV may have to be retested.

III. Risk Assessment**A. Sexual Risk Assessment**

"I'm going to ask you some personal information to help you to understand how you may be putting yourself at risk for HIV. Some of this may make you feel uncomfortable, but it is important to talk about so that you can learn how to protect yourself."

Providers should be nonjudgmental and open to any information that the adolescent may share, and should not make assumptions about an adolescent's sexual orientation/identity or sexual behaviors.

12. Have you ever been sexually active or had any sexual experiences?

- ☐ No
☐ Yes

13. If yes, how old were you when you first had sex?

Age: _____

14. Have you ever had? At what age?

- a. ☐ Oral sex _____
b. ☐ Vaginal sex _____
c. ☐ Anal sex _____

15. How old was your first sexual partner?

Age: _____

16. How many female sexual partners have you ever had? _____**17. How many female sexual partners have you had in the last 3 months?** _____**18. How many male sexual partners have you ever had?** _____**19. How many male sexual partners have you had in the last 3 months?** _____**20. Do you consider yourself _____?**

Providers should be aware of the distinction between "sexual identity" and "sexual behavior." Not all youth who engage in same-sex behavior self-identify as lesbian or gay. Male adolescents may have had anal intercourse but may not perceive themselves as being gay; similarly, lesbian adolescents may have sex with males, including anal intercourse.

- a. ☐ Straight
b. ☐ Gay or lesbian
c. ☐ Bisexual
d. ☐ Not sure

21. Have you ever _____?

- a. ☐ Traded sex for money, drugs, food, or a place to live
b. ☐ Had sex with someone who you knew was HIV+
c. ☐ Had sex with someone who has injected drugs
d. ☐ Had sex with someone who was the sexual partner of an HIV+ person
e. ☐ Had sex with someone who was the sexual partner of an IDU
f. ☐ Had sex with someone who was gay or bisexual

22. Have you ever been forced to do something sexually that you did not want to do?

Providers should be aware that many teens at risk for HIV were or currently are being sexually abused. Be alert for nonverbal cues because this type of disclosure is difficult to make. If an adolescent is being sexually abused, it must be reported, and the youth should be referred for a mental health assessment.

- ☐ No
☐ Yes (age) _____ Describe: _____

23. How often would you say that you are high on drugs or alcohol when you have sex?

- a. ☐ Never
b. ☐ Sometimes
c. ☐ Always

24. If yes, which drugs? _____**25. Have you ever been told by a doctor that you had _____?**

- a. ☐ Syphilis
b. ☐ Gonorrhea
c. ☐ Herpes
d. ☐ Chlamydia
e. ☐ Pelvic inflammatory disease
f. ☐ Genital or anal warts
g. ☐ Other STD _____
h. ☐ Not sure

26. Do you do anything to protect yourself against HIV and other sexually transmitted diseases?

If yes, what

27. How do you avoid pregnancy?

If no birth control is used, ask if there are religious or other reasons. Determine if the adolescent is having difficulty getting her partner to agree to birth control measures. This will be helpful for risk reduction intervention.

- a. ☐ Birth control pills
b. ☐ Condoms
c. ☐ Diaphragm
d. ☐ Withdrawal
e. ☐ Rhythm
f. ☐ Depo
g. ☐ Other _____

28. How often do you use condoms when you have sex?

Evaluate if use is consistent or inconsistent and identify obstacles.

- a. ☐ Never
b. ☐ Sometimes
c. ☐ Usually
d. ☐ Always

29. If you do not use a condom each time, why not?

- a. ☐ Does not like them
b. ☐ Does not know how
c. ☐ Partner does not like them or refuses
d. ☐ Cannot discuss it with partner
e. ☐ Opposed to birth control
f. ☐ I know my partners, and they do not have any infections
g. ☐ Other _____

B. Drug Use Assessment

Assess level of drug and alcohol use and context in which use occurs. Emphasize the risk of impaired judgment leading to unsafe sex. Review needle hygiene. Assess potential for addiction and treatment needs.

30. What drugs have you used?

- a. ☐ Tobacco
b. ☐ Alcohol
c. ☐ Marijuana
d. ☐ Crack
e. ☐ Cocaine
f. ☐ Heroin
g. ☐ LSD/Ecstasy/mescaline
h. ☐ Pills
i. ☐ Never used drugs

31. Which of the following drugs have you used in the last 3 months?

- a. ☐ Tobacco
b. ☐ Alcohol
c. ☐ Marijuana
d. ☐ Crack
e. ☐ Cocaine
f. ☐ Heroin
g. ☐ LSD/Ecstasy/mescaline
h. ☐ Pills
i. ☐ Never used drugs

32. Who do you usually get high with? _____

33. Have you ever used a needle for:

- | | |
|--------------------------------------|---|
| a. ☐ Heroin | e. ☐ Anabolic steroids |
| b. ☐ Cocaine | f. ☐ Tattoos/body piercing |
| c. ☐ Speed | g. ☐ Other _____ |
| d. ☐ Hormones | |

C. Blood Products

34. Have you ever had a blood transfusion?

Explain that the blood supply has been safe since 1985. (If the adolescent has received blood or blood products prior to 1985, testing may be indicated.)

- a. No
b. Yes (when?) _____

D. Maternal Transmission

Emphasize the following: Approximately 25% of infants born to mothers with HIV will be infected if the mother does not take medication; HIV also can be transmitted through breast milk. Children infected at birth may not be diagnosed until adolescence (several 14- and 15-year-olds have acquired HIV congenitally). Knowledge of parental risk for HIV will help one to assess the adolescent's risk for perinatal transmission.

*For pregnant adolescents, review the benefits of HIV testing: (1) opportunity to make decisions about the pregnancy; (2) potential for taking antiretroviral drugs to reduce transmission of HIV to their infants (describe results of ACTG 076, which showed a two-thirds reduction in maternal-infant transmission of HIV); and (3) opportunity to provide appropriate medical care for the newborn.**

IV. Risk Reduction Education

A. Decision Making and Readiness for Sexual Experience

Discuss postponing sex for youth who are not sexually active. Assess motivation for sexual behavior (e.g., experimentation, peer pressure); some youth may need support (and assistance in building communication skills) not to be sexually active. Discuss ways to feel close or have sexual, intimate pleasure without risking exposure to HIV, i.e., "outercourse" (e.g., intimate touching, including petting, and mutual masturbation do not involve the exchange of body fluids).

B. Safer Sex

Providers should explain that sexuality is a normal and positive part of life. Review the continuum of sexual behaviors from safe to unsafe. Explain that risk for HIV is increased when other STDs cause sores or lesions. Discuss techniques for negotiating safer sex with partners; use role play to model potential responses and increase confidence. Determine specific obstacles to sexual risk reduction. Discuss the following barrier methods:

1) Condom Demonstration

- Condoms must be 100% latex or polyurethane. Do not store them next to your body (e.g., in a wallet). Check expiration date on package before buying them.
- Use a water-based spermicide containing nonoxonyl-9, both on the inside tip of the condom and on the outside, during anal or vaginal intercourse (use non-lubricated condoms for oral sex).
- Do not use oil-based lubricants such as Crisco or Vaseline, which may cause holes in condoms, allowing transmission of HIV.
- Penis must be erect; leave room at tip of the condom when rolling it on; hold on to base of condom while withdrawing, using extra care if penis becomes soft.

2) Dental Dam Usage

- Used for mouth-to-vagina or mouth-to-anus sexual contact. Can substitute nonmicrowavable saran wrap.
- Use only with water-based lubricants such as K-Y Jelly; never use Vaseline.
- Place dental dam completely over mouth or anus.
- Use a different dental dam with each new partner and/or sexual activity.
- Do not use a dental dam more than once.
- Do not use it for vaginal or anal intercourse.
- Do not puncture it.

* Guidelines for offering the ZDV perinatal regimen to pregnant women are available from HRSA. (Health Resources and Services Administration: Use of Zidovudine to Reduce Perinatal HIV Transmission in HRSA-Funded Programs. Rockville, MD, Department of Health and Human Services, 1995.)

3) Female Condom

- Female condoms enable women to make the decision to use protection; male partners do not have to be erect or maintain erection to have intercourse. Product name is "Reality."
- Condom is inserted in the vagina (or anus); during intercourse, the penis must enter the condom.
- A new condom is needed for every sexual encounter. Condoms are not reusable.

4) Partner Negotiation

Role play scenarios and appropriate responses to help adolescents to learn ways to talk with their partner about practicing safer sex.

C. Safer Needle Use

- Consider demonstrating how to clean injection equipment. Explain that this is an important skill to reduce their risk for infection.
- Discuss availability of needle exchange programs.
- Tell youth not to share tattoo or ear-piercing equipment.
- Encourage drug treatment and assist in making needed referrals.

D. Sex and Drugs

Discuss increased risk due to impaired judgement. Help adolescent develop strategies to minimize or eliminate use of alcohol and drugs before and during sex.

V. Testing Issues

A. Types of Testing

1) Anonymous Testing

Explain that anonymous test sites do not use any names or other identifying information; test recipients receive a code number that identifies the blood sample sent to the lab. Information is given only to the person who gives the code number when he or she returns for results. Describe the pros and cons: although this method guarantees anonymity, it also makes it much more difficult to ensure that medical and support services are provided, especially for adolescents who have greater difficulty accessing care. Clearly explain that adolescents who test positive need to receive follow-up care, which will be provided confidentially, not anonymously. (Some adolescents may ask for anonymous testing because they falsely assume that being "anonymous" will prevent others from learning their HIV status.)

2) Confidential Testing

Confidential testing can be offered in the provider's office (or in a counseling and testing site where the sample is identified by name). In most cases, the results are available only to health providers and the person tested. Providers should be familiar with state laws related to HIV counseling and testing and provide accurate information about required or potential disclosure of results to others (e.g., parents or other agencies). Although this option may not ensure anonymity, it does enable adolescents to receive appropriate referrals for care, advocacy, and support services.

B. Meaning of HIV Test Results

1) Positive Test

A positive result means that you are infected with HIV and can infect others; it does not necessarily mean that you have AIDS. Other tests are needed to show how HIV has affected your immune system and whether or not you have AIDS.

2) Negative Test

A negative result means that you are probably not infected, but you can become infected later if you do not protect yourself. Remind adolescent of the "window period" and potential and need for retesting.

3) Indeterminate

Very rarely, test results are indeterminate, which means we are not sure if results are negative or positive. If this happens, the test must be repeated.

C. Pros and Cons of HIV Testing

35. What do you think are some of the benefits of knowing you are HIV positive?

Providers should be sure that the adolescent understands the benefits of early medical intervention, avoidance of reexposure and/or reinfection with HIV, and ability to protect others, including infants from becoming infected. Finding out early allows the adolescent to get used to the idea of having HIV before the disease progresses and to learn skills for taking care of himself or herself

36. What do you think some of the drawbacks are to finding out that you are HIV+?
Providers should point out that this news is devastating and hard to handle. Assess potential for self-harm and/or harming others. Family may be rejecting; people with HIV are stigmatized and discriminated against.

37. If you are HIV+, what would you do?
Assess for potential suicide risk. Has the youth ever attempted suicide? Does he or she have a plan? A brief role play may be helpful to anticipate reactions to test results and to identify positive coping strategies. This may elicit strong emotional reactions from some youth.

38. Whom would you inform about the positive test result? Who knows that you are being tested? On whom do you rely for support when you have problems?
If providers have not already done so, they should help to identify and to involve a supportive adult in the youth's testing decision.

D. Obtaining Consent

39. Do you feel ready to be tested today?
Determine if the youth is ready to be tested; take into account responses during the counseling session, support systems, current emotional stability, and potential for suicide.

a. ☐ Yes
b. ☐ No Why? _____
c. ☐ Unsure Why? _____

Use following checklist:

a. Does the adolescent understand that he or she has a choice about being tested, and that care will not be jeopardized if he or she decides not to be tested?
b. Does he or she indicate an understanding of the purpose and significance of the test?
c. Does he or she show an ability to anticipate a possible positive outcome?
d. Has a supportive person been identified?
e. Do they seem suicidal or homicidal?

40. Obtain written consent.
If the youth is not ready to be tested, schedule another appointment for further counseling. Be sure that he or she reviews and signs a consent form prior to drawing blood.

E. After Testing
Ask the adolescent if he or she has any questions, and assess need for interim counseling.

VI. Issues for Follow-Up and Referral

1) Strategies for Coping
Discuss how the youth anticipates coping during the waiting period. Explore ways to relieve stress and anxiety in productive ways. Give the youth a phone number to call if he or she becomes anxious or has any questions while waiting for results.

2) Partner Notification
Discuss the implications of indiscriminately telling others about having been tested (e.g., risk of discrimination). Suggest that the youth tell sexual or injection drug-using partners, and encourage partners or friends who are at risk to be tested.

3) Make Appointment for Results
Make an appointment to return for test results. (This usually takes approximately 2 weeks.) Explain that you will give results in person.

4) Follow-up and Referral
Review needs for referral and followup identified during the session and initiate as many as possible.

a. Medical
b. Psychosocial
c. School-related
d. Other

POST-TEST COUNSELING

- Negative
- I. Introduction
 - II. HIV Test Results
 - A. Meaning of negative HIV test result
 - B. Window period/retesting
 - III. Risk Reduction Review and Treatment Plan
 - IV. Skills Building
 - A. Condom demonstration and condom use
 - B. Substance abuse
 - C. Negotiating with partner
 - V. Discrimination and Disclosure
 - VI. Referral and Follow-up

Post-Test Counseling—Negative

I. Introduction
Post-test counseling may take one or more sessions. The goal is to help the youth to understand the meaning of his or her results and to reinforce healthy behavioral changes and awareness of risk behaviors. Discuss the objectives of the session, assess affect, and determine if the youth is intoxicated. If so, do not proceed with counseling until the youth is sober; this may require waiting for a period of time or rescheduling the appointment and asking him or her not to use substances before the session.

II. HIV Test Results

"I am going to give you your results, and we will discuss what they mean. Your HIV test came back negative, which means you do not have antibodies to HIV right now. But we need to make sure you stay negative."

Allow time for the youth to respond; show the lab slip to reinforce understanding of results. Ask if the youth is surprised, and what his or her expectation was. Explore reactions (e.g., "survival guilt"—some may feel guilty or disbelieving, particularly if a partner is infected).

A. Meaning of negative result
Discuss and clarify meaning of negative HIV test result. Explain that the test results do not mean that he or she is immune to HIV.

B. Window period/retesting
Explain the window period and need for retesting within 6 months if the youth has engaged in risky behavior during the past 6 months.

III. Risk Reduction Treatment Plan
"You have had a negative result. We need to make sure it stays that way. Let's develop a simple plan to help to keep you from getting infected."

Review and reinforce the adolescent's knowledge of risk reduction behaviors. Assess commitment to practicing them. Develop an individualized risk-reduction treatment plan on the basis of changes (or lack of changes) adopted since the pre-test. Remain open and nonjudgmental to create a safe environment for discussion.

Goal	Strategy	Obstacles	Success

IV. Skills Building

A. Condom demonstration and condom use
Review condom demonstration, supply condoms, initiate role play to help youth to introduce them during sexual encounters. Help to identify ways to eroticize condom use.

B. Substance Abuse

Review risks created by substance use before and during intercourse. Although sharing needles represents the most direct route for HIV infection, other substances (e.g., alcohol, marijuana, intranasal heroin, and cocaine) impair judgment and increase potential for risky behaviors.

C. Negotiating with Partner

Encourage the adolescent to discuss HIV with his/her sexual and/or drug-injecting partner. Use a role play to discuss bringing the partner in for counseling, risk-reduction education, and testing.

V. Disclosure and Discrimination

Caution the youth about indiscriminately telling others that he or she has been tested, because people can be discriminated against just for being at risk for HIV. Provide information about what to do if he or she experiences discrimination, including advocacy referral resources.

VI. Referral and Follow-up

Ask the youth if there are any questions. Make appropriate referrals for follow-up care, mental health services, or social services while the youth is still in your office. Ask how the youth would like to be contacted (e.g., in some cases, the adolescent may not want parents to know that he or she is seeking certain kinds of services).

Provide health education literature. Schedule another post-test counseling session, if indicated; schedule follow-up testing in six months, if required.

POST-TEST COUNSELING**Positive****I. Introduction****II. HIV Test Results****III. Implications of Positive HIV Test Result****IV. Risk Reduction Review****V. Skills Building**

- A. Condom demonstration and condom use
- B. Substance abuse
- C. Negotiating with partner

VI. Discrimination and Disclosure**VII. Referral and Follow-Up****Post Test Counseling—Positive****I. Introduction**

Assess the adolescent's affect and determine if he or she is intoxicated. (If so, do not proceed with counseling until the youth is sober; this may require waiting for a period of time or rescheduling the appointment.) Explain the goals of the counseling session (to help the youth to understand the meaning of his or her results and to reinforce healthy behavioral changes and awareness of risk behaviors).

"I am going to give you your results, and we will discuss what they mean."

II. HIV Test Results

Give the test results and show the laboratory slip. Allow time for the youth to respond; ask if the youth is surprised, and what his or her expectation was. Provide emotional support. Allow him or her time to react and to express feelings. Assess level of shock and denial. Do not push the youth to proceed until he or she clearly is ready to. Assess potential for traumatic emotional reaction and suicide throughout the session.

"Your test results show that you have antibodies for HIV; this means that you have been infected with HIV."

III. Implications of a Positive Result

Discuss the difference between being HIV-infected and having AIDS. Offer hope/optimism for continued health and quality of life. Explain that AIDS is a chronic illness, not a death sentence, and that regular medical care will help to maintain health and help to identify health problems before they become serious.

"A positive result means that you have antibodies to HIV in your blood. This means that you are infected with HIV. Another way to say this is that you are HIV-positive or seropositive. It is important to get regular medical care so that you can find out what stage of HIV infection you are in and receive appropriate treatment. When you are infected with HIV, the virus slowly weakens your body's ability to fight other infections. New medical treatments can help your body to fight HIV by slowing the growth of the virus and delaying or preventing certain life-threatening conditions. If you get prompt and regular medical care, you can delay getting AIDS and prevent serious infections. It is important to remember that HIV infection is a chronic illness, not a death sentence. People can live healthy and productive lives, even though they are infected with HIV."

A. Antiretroviral perinatal risk reduction (pregnant adolescents)

If the adolescent is pregnant, discuss the option of taking antiretroviral drugs to reduce the risk of perinatal transmission. Provide patient education materials; review benefits and potential risks; answer questions; and provide an opportunity for followup and family counseling to support decision-making.

IV. Risk Reduction Review

The emphasis of an initial post-test visit for HIV-positive adolescents is coping with their new health status and linking with services and care. Risk reduction skills can be mentioned but are not the focus of the visit. Review of dos and don'ts includes the following:

- | | |
|--|---|
| <i>Do not donate blood, semen, tissue,
or body organs.</i> | <i>Do not share needles</i> |
| <i>Do not share razors or toothbrushes.</i> | <i>Do practice safer sex</i> |
| <i>Do not breast feed.</i> | <i>Assess risk behaviors and commitment
to risk reduction strategies.</i> |

V. Skills Building

Emphasize the importance of engaging in safer sex, even if youth is not ready to notify his or her partner.

A. Condom demonstration and condom use

Review condom demonstration, supply condoms, initiate role play to help youth to introduce them during sexual encounters. Help to identify ways to eroticize condom use.

B. Substance abuse

Make sure the adolescent understands that sharing needles (IV drug use) represents the most direct risk for HIV infection, but use of alcohol and other drugs (e.g., marijuana, intranasal heroin, and cocaine) impairs judgment and increases the potential for risky behaviors.

C. Partner negotiation/notification

Encourage the adolescent to discuss HIV with his/her sexual and/or drug-injecting partner. Use a role play to discuss bringing the partner in for counseling, risk reduction education and testing.

VI. Disclosure and Discrimination

Discuss the need for disclosure to the adolescent's past partners, family, and dentist. Offer to provide assistance and support in notifying others, if needed. Caution the youth about disclosing his or her HIV status more extensively because discrimination against people with HIV is widespread. Provide information about what to do if discrimination occurs.

VII. Referral and Follow-up

Discuss referral and follow-up needs identified during the session (e.g. general medical care, rape crisis, battered women's services, drug treatment); schedule a follow-up appointment; and initiate referrals while the youth is still in your office. Discuss appropriate entitlement programs, e.g. ADAP (AIDS Drug Assistance Program). Be clear about how the youth would like to be contacted by other agencies.

Review the adolescent's support system and develop a plan for getting appropriate support during the next week. If a supportive adult has not accompanied the youth for test results, ask: "What are you going to do when you leave this office? Are you going to call _____ (identified support person)?" Provide emergency contact numbers (e.g., 24-hour crisis hotline, emergency mental health services) and information on how to contact you, if necessary.

Ensure that the adolescent is emotionally stable before terminating the session. At a later date discuss legal, housing, school and employment rights.



National AIDS Policy Center

For Children, Youth & Families

Todd -

Thank you
for taking care
of signing the

letter from

President Clinton.

I look forward to
working with you
in the future -

Maureen

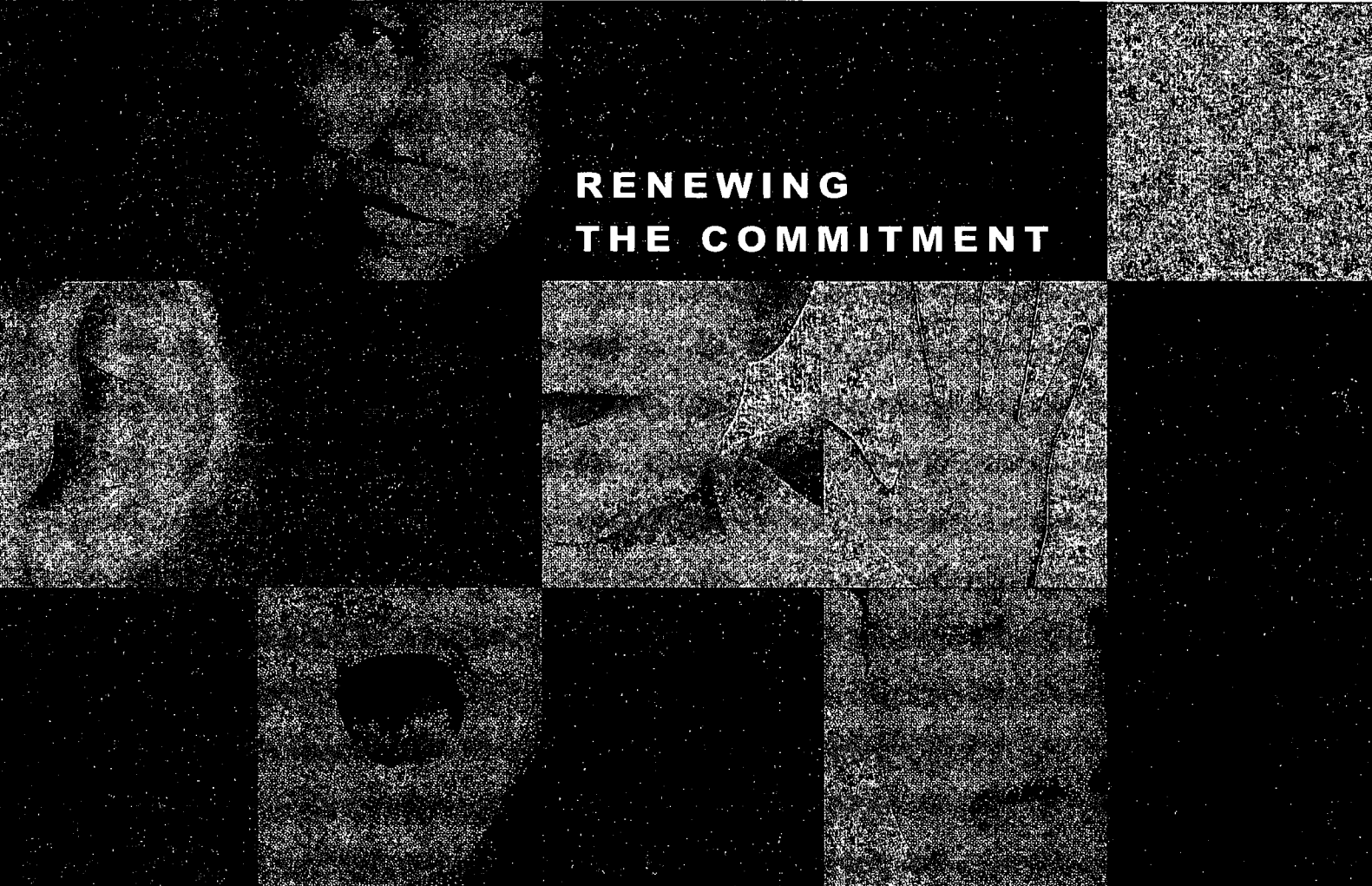
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