HRSA
HEALTH RESOURCES AND SERVICES ADMINISTRATION
HIV/AIDS Bureau

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TA CALL REPORT

HIV/AIDS National TA Calls are an ongoing series of national teleconferences for the CARE Act community to address issues raised by grantees, planning body members, and service providers. Started in 1994, the series is sponsored by HRSA's HIV/AIDS Bureau, Division of Training and Technical Assistance. The hour-long call format includes presentations by CARE Act grantees and others, along with opportunities for listener comments. Past TA call reports can be found at www.hab.hrsa.gov

INSIDE:

Serving HIV Positive Youth

The face of the HIV epidemic is increasingly young. In the U.S., an estimated one in four new HIV cases are 13-21 years old. Half of all new HIV infections are thought to occur among those younger than 25.

Various CARE Act providers around the nation are responding to the epidemic's increased impact on youth by undertaking efforts to better link HIV-positive youth into care. Their ideas—and HRSA's perspective on the importance of outreach to reach those not in care—are presented in this issue of *TA Call Report*, which summarizes the June 12, 2000 National TA Conference Call. Featured are the following:

- **Epidemiologic data on youth and HIV/AIDS**. Youth most impacted by HIV/AIDS include sexually active gay/bisexual men (particularly men of color), young women, and disenfranchised populations such as homeless, runaway, and street-involved youth. (Use of local data in identifying populations most affected is important given variations across geographic areas.)

- **The HRSA HIV/AIDS Bureau (HAB) perspective on the CARE Act's role in prevention and care**. The CARE Act role is to reach underserved populations impacted by HIV/AIDS—including youth—in order to link them into care. The most important tools are epidemiologic data to

(Continued on page 2)

HRSA/HAB Perspective

CARE Act Role in Reaching HIV-Positive Individuals

Joseph O'Neill, M.D., M.P.H.
HRSA Associate Administrator for HIV/AIDS

The role of CARE Act providers in reaching HIV-positive youth—and others impacted by HIV—is to link them into care as early as possible. This is the field of early intervention and bridges both prevention and care, which are usually thought of as two distinct fields.

From the point of view of the client, care and prevention are the same thing. A patient at a clinic isn't likely to make a distinction between when the clinician is talking prevention (like giving information about risk reduction) or care (such as using medications properly). CARE Act programs need to think like their customers. HRSA and CDC have moved in this direction to bridge the gap in the prevention-care continuum. Examples include HRSA participation in the development of a national five-year HIV prevention plan being spearheaded by CDC. (For more on CDC/HRSA collaboration, see http://www.hab.hrsa.gov/tools.htm.)

(Continued on page 3)

Youth Initiatives of HRSA/HAB

Following are initiatives of HRSA's HIV/AIDS Bureau focused on HIV-positive youth.

- **SPNS Demonstration Models for HIV-Infected Youth**. SPNS projects, which test innovative demonstration projects serving underserved populations, have targeted youth and others. Examples include use of street outreach workers to conduct acute crisis intervention. Insights can be viewed at http://www.hab.hrsa.gov or http://www.elsevier.com/locate/jahonline or by calling the SPNS program at 301-443-9976.

- **Title IV Adolescent Services Initiative**. Clients include HIV-infected youth 13-24, with an emphasis on those 13-19 years. Service networks of youth-sensitive providers deliver a continuum of care that links counseling and testing, primary medical care, supportive services, and opportunities for clinical research. To learn more, see http://www.hab.hrsa.gov or call 301-443-9051.

- **Project Access.** This HRSA co-sponsored social marketing program promotes HIV counseling/testing among at-risk youth to link those infected to care (see page 9).

- **White House Report on HIV/AIDS and Youth**. Prepared by a collaborative group including HRSA, the report summarizes the state of youth and HIV in the U.S. and presents policy recommendations. To learn more, see http://www.whitehouse.gov/ONAP/youth_report.pdf or call the White House Office on National AIDS Policy at 202-456-2437.

- **HAB Cooperative Agreements**. Youth-focused materials developed through HAB partnerships with national organizations include resources by the National Pediatric and Family HIV Resource Center (http://www.pedhivaids.org), AIDS Alliance for Children Youth and Families (http://www.aids-alliance.org), and the National Association of People With AIDS (http://www.napwa.org).

- **Lesbian and Gay Youth: Care and Counseling**. This HRSA-funded book outlines strategies for working with sexual minority youth. Call 301-443-6652 to learn more.

Serving Positive Youth

(Continued from page 1)

target outreach and planning efforts; collaboration with youth-serving agencies; and adopting lessons learned from other CARE Act programs on how to best reach and serve youth.

- **CARE Act community insights on accessing and serving HIV-positive youth**. Speakers on the call provided insights on serving HIV-positive youth, such as: use of flexible outreach/HIV counseling and testing efforts like peers and street-based testing; coordination with youth-serving agencies to create a continuum of youth-sensitive services; and the importance of specific services (e.g., transportation, adherence assessment and support) to help youth access and remain in care.

For more on HIV and youth, see "HIV Care for Sexual Minority Youth" in the November/December 1999 issue of *HRSA CareACTION*, the HIV/AIDS Bureau's newsletter on HIV/AIDS care, available at http://www.hab.hrsa.gov (under Publications) or by calling 301-443-6652.

Grantees from St. Louis, New York, and San Francisco joined HAB staff in presenting their insights on the call. Listeners from across the nation added comments during Q/A periods on such topics as dealing with youth suicide and serving homeless youth.

HRSA/HAB Perspective

CARE Act and Reaching HIV-Positive Individuals

(Continued from page 1)

Primary Care Includes Prevention. The definition of primary care also helps clarify how prevention falls within the realm of care. The Institute of Medicine's definition of primary care includes acute and chronic care, and handling of referrals as primary care services and says that "prevention and early diagnosis…including screening, counseling, risk assessment, and patient education" are part of primary care. HRSA concurs with this definition and expects primary care providers to emphasize prevention services as appropriate.

CARE Act and Prevention. This definition of primary care does not signify a shift in HRSA's guidance on use of CARE Act funds. The CARE Act mandate is to provide primary care and supportive services—including prevention services—to underserved persons with HIV. Over the years, the HIV/AIDS Bureau has clearly stated that allowable uses of CARE Act funds for prevention services means that they must focus on helping link people with HIV disease into care.

CARE Act resources cannot be used to pay for prevention activities like public information campaigns and educational brochures. The CARE Act's role is not to take on general education of youth in the schools. Those are activities under the framework of CDC prevention funds, which involve education targeting uninfected populations and risk reduction for infected individuals.

Challenges in Reaching HIV Positive Youth. The prevention role of the CARE Act must focus on linking people with HIV disease into care and, for those already in care, helping prevent progression of their HIV disease. This challenge is significant for multiple reasons:

- An estimated one-third of persons with HIV do not know their status and are not in care. Adolescents tend to be underserved by traditional HIV counseling/testing services for adults. Adolescents who are tested are less likely to return for their test results as compared to others. Many adolescents with HIV learn their HIV status late in their disease, often when they become symptomatic.

- There is a 1-5 year lag in the time between learning one's HIV-positive test results and seeking primary care. Adolescents may be particularly underserved by services designed for adult patients. HIV-infected youth in particular are often in unstable living situations, making it difficult for them to access care.

In responding to these challenges, CARE Act providers should consider the multiple insights contained in this report on ways to better reach and serve youth living with HIV/AIDS.

What You Thought of the Call

Listeners rated the call a 4.0 on a 5-point scale (5 is best). Suggested was more call time for Q/A and grantee presenters from rural, Southern, and Midwestern states. Also recommended: sharing of more innovative ideas on working with HIV+ youth, such as adherence, working with specific ethnic groups, and youth testing issues (e.g., testing in schools, confidentiality, parental involvement, partner notification).

What Can CARE Act Providers Do?

Understand who is infected to guide outreach and care efforts. Some CARE Act grantees have reported difficulties finding HIV-positive youth. Use HIV and AIDS data to help determine where cases are in order to target efforts. Programs should work with health departments—which CARE Act planning processes typically do—in reviewing HIV/AIDS case data, case estimates, and other information useful to developing programs.

Build linkages with youth-serving agencies, particularly those working with high risk youth. Examples include juvenile corrections, maternal and child health, and runaway and homeless agencies. Agencies that work with gay/bisexual youth and women, especially African American and other communities of color, are crucial in addressing the significant numbers of HIV and AIDS cases among these groups.

Use information about what works. Insights from CARE Act projects include Special Projects of National Significance (SPNS) and Title IV Adolescent Initiative grantees (see page 2)—as well as lessons from other CARE Act grantees.

Joseph O'Neill

Insights on Reaching and Serving HIV-Positive Youth

Presenters on the National TA Call shared an array of ideas on how to reach and serve HIV-positive youth, including recommendations to:

- Conduct outreach and offer HIV counseling/testing in creative ways (e.g., oral HIV testing, street-based, peer-based).
- Coordinate with other agencies, particularly youth-serving groups, in order to reach and expand access to young clients.
- Tailor services to meet needs of adolescents (e.g., case management, adherence support, sensitivity to sexuality, helping youth understand complex medical issues).
- Involve youth in their care and in program planning (e.g., as peer educators, as sources of information on designing programs).

Speaker insights in these areas are presented below.

Conduct Outreach, Creatively Offer HIV Counseling/Testing

Of the estimated 100,000 youth infected with HIV, most are unaware of their status and thus are not in care. A first step for programs is helping youth learn their HIV status. Outreach and street-based HIV counseling and testing are key tools since youth at highest risk are less likely to access services, including HIV counseling/testing offered in traditional public health settings. National TA call presenters suggested the following:

- **Normalize HIV counseling and testing among sexually active youth.** Prevention-only messages are not enough. HIV counseling and testing should be a regular part of HIV prevention programming.
- **Routinely offer HIV counseling and testing and expand the number of settings where it is offered**. This includes street-based and field settings in addition to clinic-based facilities.
- **Conduct outreach/case finding in creative ways**. Multiple grantees use peer educators and outreach staff.

Following are examples of outreach and HIV counseling/testing activities of CARE Act grantee presenters:

- Outreach vans are used by the William F. Ryan Community Health Center, a Title III and I grantee, to conduct HIV counseling/testing, including oral HIV testing. They use a full-service medical van and a scaled-down vehicle that is less costly to operate. HIV counseling and oral HIV testing is also offered in their teen clinic ($5 flat fee for full medical session). Staff explain confidentiality and consent to care rights when clients come in for care. The Ryan Center also uses its outreach vans and other youth-serving agencies as sites for stationing peers in neighborhoods where youth congregate. Peers tell agency staff where youth at risk are each week so they can be contacted later. Peers also help youth at risk to access service in such ways as accompanying them to appointments (escort services).

(Continued on page 5)

Facts: Youth & HIV

- One in four new HIV cases are estimated to be among persons 13-21 years old; half of all new HIV infections in the U.S. are thought to occur among those younger than 25.
- While AIDS incidence—new cases during a time period—is declining, a comparable drop has not been seen among newly diagnosed youth HIV cases, according to a CDC study in 25 states.
- Youth HIV/AIDS cases are disproportionately among men who have sex with men (MSM), sexually active women of color, African American and Hispanic youth, runaway/homeless youth, and injection drug using youth.

Young People at Risk: HIV/AIDS Among America's Youth, http://www.cdc.gov/hiv/pubs/facts/youth.htm

Insights on Reaching and Serving HIV-Positive Youth

Coordinate Services to Enhance Access

Collaboration among agencies, particularly HIV/AIDS and youth-serving agencies, is critical for several reasons:

- **Youth-serving agencies, particularly those working with high risk youth, are key access points in reaching youth at highest risk for HIV**. This includes juvenile corrections, maternal and child health, and runaway and homeless agencies. Most crucial are agencies that work with gay/bisexual youth and women, especially African American and other minority populations, given the significant numbers of HIV and AIDS cases among these groups.

- **Youth have multiple care and support service needs, which may best be provided by linking with others**. Many non-medical services can help break down client barriers to accessing both prevention and primary care services. For example, transportation can help overcome barriers to enrollment and retention in primary care.

- **Because youth-specific care services are few in number, it is important that current agencies in the same geographic area link together**. This can help enhance the continuum of care for youth. Boston-area agencies help make this happen through a monthly adolescent AIDS networking breakfast and a quarterly community planning committee meeting.

(Continued from page 4)

Conduct Outreach, Creatively Offer HIV Counseling/Testing

- New York's Project Access, a HRSA-sponsored social marketing campaign promoting HIV counseling and testing, offers testing in non-clinic settings (e.g., schools, youth centers, recreation sites, housing projects, youth social networks).

- Multiple projects have found that oral HIV testing can facilitate outreach because it makes it easier to move counseling and testing services out of the clinic. Youth may also find it more acceptable than having blood drawn. Urine testing is another option, which can also screen for chlamydia and gonorrhea.

- San Francisco's Larkin Street has a street-based outreach program to link youth to care. Staff are trained in outreach, HIV testing, and treatment advocacy. Outreach is based in areas where homeless youth congregate. Larkin Street also collaborates with two agencies in targeting African American female street workers and Asian and Pacific Islander youth, conducting joint street outreach, and offering testing at their sites.

- Case finding is the responsibility of all Larkin Street staff—not just those in their HIV program. All staff are trained in HIV testing, which has helped increase the number of HIV tests because more youth are reached.

Three principles guide New York City's Ryan Center (a Title III grantee that also receives Title I funds) in working with teens: (1) use peer educators to do case finding and outreach; (2) offer HIV counseling and testing in the field; (3) make it easier for youth to get into care.

SPNS Insights:

Reaching HIV Positive Youth of Color

SPNS projects suggest reaching minority youth with HIV through:

- Peer Counseling
- Community education (via group or one-on-one street outreach)
- Training and consultation on HIV service and intervention needs of agencies
- Coordination of local services for youth

For more, see the HRSA HIV/AIDS Bureau website: http://www.hab.hrsa.gov

Insights on Reaching and Serving HIV-Positive Youth

Tailor Services to Meet Specific Adolescent Needs

Individual youth clients vary in their service needs. Examples include housing-related care for homeless/street involved youth; coping with sexuality for sexual minority youth; outreach and services to young women of color to address cultural issues and access to HIV and reproductive care; and transitioning to adult care for the growing number of HIV-positive youth perinatally-infected and surviving through adolescence.

Following are insights shared by call presenters on tailoring of services to meet such varied needs.

- **Some youth need intensive case management in order to remain in care**. Case management needs to occur across sites and must include follow-up and frequent phone contact. Half of Boston HAPPENS youth clients do not have any health insurance and need particular assistance with accessing services. SPNS project experience is that 10-20 active cases is an appropriate caseload for youth-oriented case managers.

- **Be sensitive to cultural issues of clients—including race, ethnicity, and sexuality**. Cultural sensitivity includes race and ethnicity, gay identity, and understanding high risk environments in which many young people live. Some young people are still in the process of disclosing sexual identity when initially diagnosed with HIV. Providing youth with a place where they can accept their sexuality allows them to become comfortable with who they are. According to Lawrence Lewis, Project ARK in St. Louis, not every young client infected through same sex relations considers himself gay. Therefore, they provide time for youth to self-identify when they feel ready.

- **Service needs evolve for HIV-positive youth perinatally-infected who are now surviving through adolescence and into adulthood**. Children with HIV may find compliance with treatment regimens more difficult as they move into their teens since they are less reliant on parents and other care givers. In some cases, parents incorrectly assume their teen children are more capable of managing their medications. But adolescence stands in the way given the evolving sense of self and developmental challenges that youth face.

- **Adapt and adjust services as the area's client profile changes.** This is necessary to keep services appropriate to those being served. San Francisco's Larkin Street developed a residential component for HIV-positive youth in response to the growing number of youth with AIDS who were dying alone in hotel rooms and apartments. The program was also modified over

(Continued on page 9)

Taking time to assess an adolescent's readiness to begin and maintain a complex antiretroviral regimen is one of the key messages in *Helping Adolescents With HIV Adherence to HAART*, a report developed by the Adolescent Medicine HIV/AIDS Research Network and published by the HRSA HIV/AIDS Bureau in 1999. To obtain a copy, call the HRSA Information Center at 1-888-ASK-HRSA.

Tips for Serving Youth With HIV

- Provide services that are easy for youth to access.
- Location is important.
- The more comprehensive the services provided, the better.
- If everything cannot be brought to one site, provide transportation.
- Assess where barriers are and deal with them.
- Collaborate with partners who add to the continuum of services your organization wishes to provide.
- Talk with and listen to consumers (e.g., focus groups, advisiory boards, peer leaders).
- Hire consumers in paid internships or jobs if possible.

Insights on Reaching and Serving HIV-Positive Youth

Involve Youth in Their Care

Multiple agencies have engaged youth in the planning and provision of their own care. This has helped programs become more sensitive to youth and provided a role for youth as service providers. Youth involvement can take such forms as: youth staff, peer leaders, co-leaders of support groups and community events, and members of youth advisory boards and planning groups.

- Adolescent focus groups convened in Boston provided feedback that youth want to receive care at a variety of accessible and appropriate sites. This helped guide planning to deliver care at multiple sites.
- Larkin Street also used youth focus groups in crafting its program. When they first offered confidential HIV testing in 1989, they noticed that young people would "disappear" after receiving test results, declining to use the on-site medical clinic. They asked a focus group of youth what was the most important service and were unanimously told it was "housing." The agency started a housing facility for 10 youth in 1990 and in eight years were serving 90 clients. Once the basic need of housing was addressed, the utilization rate of the medical clinic and other services increased. The drop-in rate of youth using the clinic also increased as the once-dismal retention rate rose to above 90 percent.

Helping Youth With HAART

Adherence to complex treatment regimens is a challenge for all clients and particularly adolescents. Youth need particular help in assessing their readiness to begin treatment and—once initiated—maintain compliance over time. Among the thoughts of call presenters:

- **Youth may be discouraged from taking medications properly when they fail to see improvements and suffer side effects**. They may internalize drug failure as their own, said Lawrence Lewis of St. Louis in his comments on the national TA call.
- **Young people require treatment regimens and clinical trials that are simple and easy to incorporate into their daily schedules**. Providers therefore must balance the medically ideal with a treatment plan suitable to the individual client. Care teams need to work with each client to adjust complex treatment regimens to their lifestyles, personal needs, and daily schedules. Importantly, providers need to accommodate adolescent developmental stages and thinking. This includes helping young clients cope with their HIV status, assess readiness to begin treatment, adhere over time, and address concerns like confidentiality.
- **Clear communication between providers and clients about the complexity of treatment is crucial**. Lewis said that medical jargon is confusing to many youth, regardless of educational background. Citing work with his clients at Project ARK in St. Louis—and his experience as a young man living with HIV—Lawrence told call listeners that youth face major language barriers about complex medical terms. Clinicians, in turn, may not understand youth slang. Project ARK confronts communications barriers by having case managers attend medical visits with clients having problems communicating with their doctors.

What is the Continuum of Care for Youth?

Boston HAPPENS has outlined an example of what the continuum of care for youth HIV services might include:

- HIV prevention and education
- Street and community outreach to at-risk youth
- Basic need services such as food, shelter, transportation, employment, and child care
- Drop-in centers for street and homeless youth
- HIV counseling and testing services
- Primary care
- Mental health services
- Inpatient and specialty care when needed

Presenters on the National TA Call

Donna Futterman, M.D., M.P.H.
Montefiore Medical Center
New York, NY
718-882-0322

Dr. Futterman of Montefiore's Adolescent AIDS Program discussed policy issues in serving HIV+ youth (e. g., consent); the need for prevention to address sexuality and counseling and testing; outreach and linkage to care as a key medical issue; developing and sustaining youth-centered programming that offers an array of services; and ensuring financial access to care including the role of managed care in care delivery.

Montefiore, which receives Title III and AETC funding, is a comprehensive care program serving HIV + at risk youth 13-21. The program also conducts research, outreach and training.

Dr. Elizabeth Woods, M.D., M.P.H.
Boston HAPPENS
Boston, MA
617-355-6495
woods@a1.tch.harvard.edu
http://www.childrenshospital.org/adolescent/happens

Dr. Woods, Director of Boston HAPPENS (Boston HIV Adolescent and Provider Peer Education for Network Services), discussed the need for a continuum of care for HIV-positive youth and issues around reaching, engaging, and retaining youth in care.

Boston HAPPENS, a SPNS adolescent project, implements a citywide network of HIV care for at-risk, HIV-positive and homeless youth. Care is tailored to adolescent developmental/cultural needs and includes such services as outreach, counseling, screening and service needs assessment, follow-up, and communication among providers. The program serves 2,000 youth 12-24; 54 clients are HIV-positive.

Denise Albano, Mike Kennedy
Larkin Street Youth Center
San Francisco, CA
415-673-0911
http://www.lsyc.org

Ms. Albano and Mr. Kennedy discussed Larkin Street's model of housing and care/support services.
Larkin Street Youth Center serves homeless and runaway youth. The Larkin Street model is based on a two-prong approach integrating comprehensive psychosocial and support services with a housing program. They offer youth a continuum of 13 different services at seven separate sites. HIV services are located at the same site and include an aftercare program, assisted care program, and HIV specialty medical clinics. Programs provide comprehensive services for homeless and runaway HIV+ youth 18-23.

Larkin Street is a Title IV grantee.

Lawrence Lewis
Project ARK
St. Louis, MO
314-535-7275
LEL1029@aol.com

Mr. Lewis, Youth Prevention Specialist for Project ARK, provided his perspective as a consumer and a provider of services for youth. He discussed cultural competency for such youth concerns as sexuality, confidentiality, and communicating medical information in understandable terms; the challenge of adherence to complex antiretroviral regimens; and the role of specific services in overcoming access to needed services.

Project ARK is a Title IV grantee.

Will Murphy
William F. Ryan Community Health Center
New York, NY
212-316-7956
Wmurphy@ryancenter.org
http://www.ryancenter.org

Mr. Murphy Director of Special Programs and Outreach Services for the Ryan Center, shared principles that guide his agency's work with teens, including outreach and street-located HIV counseling/testing, use of peers, and co-location of peers in community and youth agency settings.

The Ryan Center, located in New York City, is a Title III grantee that also receives Title I funds and provides multiple outreach and primary care services to adolescents and young adults.

National Youth Campaign Promotes HIV Counseling/Testing

Project Access is a social marketing initiative that promotes HIV counseling and testing among youth through a combination of marketing, advertising, and community outreach. The project uses youth language in making the link between having sex and the need to get HIV tested. The project is funded by HRSA with co-sponsorship by the National Institutes of Health with Congressional Black Caucus Health Emergency funds. Six communities—Baltimore, Los Angeles, Miami, New York, Philadelphia, and Washington, DC—served as marketing sites.

A basic principle of the campaign is youth leadership in outreach and message delivery—and speaking to youth in their own language. The campaign has mobilized over 2,500 youth as activists and peer educators. Health and community coalitions built in each city provide free and accessible voluntary counseling and testing. Over 1,000 youth have been tested to date. Campaign insights include:

- **Outposting of counseling/testing is an effective method of reaching youth**. It should occur where youth are located (e.g., schools, youth centers, recreation sites, housing projects, youth social networks).
- **Oral HIV testing facilitates outreach efforts**. Counseling and testing services can easily move out of a clinic setting and youth find the oral test more acceptable than drawing blood.
- **The campaign has successes but is not a magic bullet because a sustained effort is needed**. Maintaining behavioral practices and changing youth norms requires support and reinforcement over time.

Tailor Services to Meet Specific Adolescent Needs

(Continued from page 6)

time so that homeless youth with HIV could better access primary care and antiretroviral treatments.

- **Look for ways to enhance access to needed services**. Obstacles to care vary according to unique situations of clients. For example, transportation vouchers paid for by Title I in St. Louis help youth get to various service sites. Larkin Street in San Francisco provides housing to homeless youth and St. Louis' Project ARK links with housing providers to secure shelter for homeless youth clients.
- **Youth want to receive care at a variety of accessible and appropriate sites.** In Boston, feedback from youth focus groups was that young clients want an array of service sites, such as school-based health centers, community health centers, storefront clinics, and adolescent/young adult hospital practices. Care sites should be culturally and developmentally appropriate for young people (e.g., providers trained in interacting with young patients). Young people tend to avoid clinics where the sign over the door indicates a diagnosis (e.g., sexually transmitted diseases, HIV/AIDS, or pregnancy clinics) and seek confidential, comprehensive care settings. Some prefer the anonymity of a larger hospital setting and frequently desire a different site from where their parents receive care.

Strategies To Help Youth Learn Their HIV Status

Normalize HIV counseling and testing among sexually active youth. This means going beyond prevention messages in the prevention realm and including counseling/testing within the continuum of care services.

Routinely offer voluntary counseling and testing and expand the number of settings where it is offered. This strategy should be similar in scale to the routine offering of prenatal counseling and testing.

Project Access websites:

www.adolescentaids.org

www.hivlivewithit.org