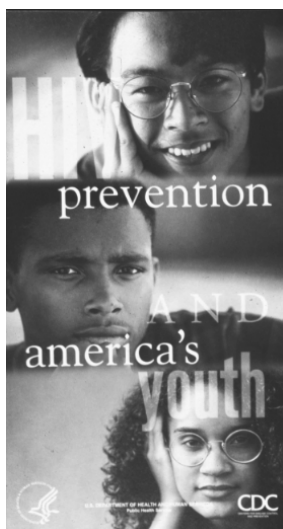


## THE RESPONSE:

Since the release of the 1996 ONAP report to the President, *Youth and HIV/AIDS: An American Agenda*, significant progress has been made. Prevention and care programs for young people have been strengthened, and research has generated important new medical treatments. However, many young people who are either infected with HIV already or at risk of HIV infection have not benefited from the advances of the last several years. Reaching all of our youth will take additional resources, coordinated effort, and the political will to support proven strategies.

## PREVENTION RESPONSE:

The Federal government supports a wide range of programs to prevent HIV infection, most of which are administered by the CDC. Other Federal agencies also play key roles. Between FY 1996 and FY 2000, Federal funding for HIV prevention programs increased from \$638 million to \$1.057 billion.



Federal agencies and offices support state and local HIV prevention programs both financially and technically. For example, the DHHS Office of Minority Health (OMH) funds local prevention programs that use strategies ranging from teen theater to peer counseling to prevent HIV among minority youth. OMH also provides technical assistance in the development of organizational infrastructure. This assistance helps minority organizations and coalitions become stable, ongoing sources of prevention services. OMH also helps prevention service providers deliver messages in formats that are likely to be acceptable to minority youth and their families.

### Spreading the Word about HIV

**The National AIDS Hotline (1-800-342-2437)** is a free source of answers to basic health questions. It also offers referrals for service and for more in-depth information. Between July 1999 and June 2000, the AIDS Hotline received approximately 143,580 calls from people ages 18-24, and 39,484 calls from people under age 18. A National STD Hotline received thousands more. In addition, the AIDS Hotline's "Classroom Calls" program reached more than 4,000 young people.

The National Prevention Information Network (NPIN) provides in-depth information about HIV/AIDS, STDs, and tuberculosis. Through a toll-free telephone line (1-800-458-5231) and a web site (<http://www.cdcpin.org>), NPIN serves thousands of researchers, educators, health care professionals, parents, and young people each year. NPIN also links the public to other Federal information sources such as the Office of Minority Health Resource Center ([www.omhrc.gov](http://www.omhrc.gov), 1-800-444-6472), the AIDS Treatments Information Service (ATIS) (1-800-HIV-0440), and the AIDS Clinical Trial Information Service (ACTIS) (1-800-TRIALS-A) maintained by the National Institutes of Health (NIH).

## Monitoring the HIV/AIDS Epidemic

CDC monitors various aspects of the HIV/AIDS epidemic by age group on a continuous basis. A number of surveillance tools are used to track youth and adult risk behavior, HIV tests given at publicly funded sites, reported cases of HIV and AIDS, and AIDS-related deaths. These statistics are stripped of any information that could identify individuals and reported by states and local areas to CDC. CDC compiles the statistics, analyzes them, and makes them available to the public on the **worldwide web** ([www.cdc.gov](http://www.cdc.gov)) and in libraries across the country.

In addition to ongoing surveillance, special studies are conducted by NIH and CDC when there is a need for additional information on particular risk groups. For example, the Young Men's Study gave HIV tests and interviews about risk behavior to thousands of young men who have sex with men in seven large U.S. cities, and then repeated these procedures several years later. This allowed scientists to gauge trends in HIV-relevant knowledge, attitudes, and behavior and in HIV infection rates among members of this high-risk group.

Between FY1996 and FY2000, CDC funding for domestic HIV prevention increased from \$584 million to \$695 million. A large portion of this funding supports HIV and AIDS surveillance (*see sidebar on Monitoring the Epidemic*), efforts to ensure a safe blood supply, and laboratory research (e.g., on microbicides). This funding is also the major source of Federal financial support for community-based HIV prevention programs. Through cooperative agreements with health departments, CDC supports all 50 states, seven territories, the District of Columbia, Puerto Rico, and six high-incidence cities in conducting a variety of HIV prevention activities. They include voluntary HIV counseling and testing, health education and risk-reduction, public information, and community planning.

Community planning is a process that allows community volunteers and health department staff to set priorities for local HIV prevention activities funded through the cooperative agreements with CDC. During FY 1999, \$268 million went to local areas through the cooperative agreements, and Community Planning Groups (CPGs) allocated about \$56 million to local organizations that provide community-based prevention programs to youth.

The 1996 ONAP report recommended greater youth involvement in the CPGs. The National Association of State and Territorial AIDS Directors was funded by CDC to compile a case study of CPG experiences with youth involvement. Several other national organizations also have been funded to increase youth involvement.

CDC also awards funding directly to some local organizations—mainly those that provide prevention services to hard-hit racial and ethnic minorities. Eighty-four of these grantees serve youth, and many of them serve other age groups too.

In addition, CDC receives and distributes about \$45 million per year for HIV prevention activities in secondary schools, post-secondary institutions, and settings that serve youth in high-risk situations. The funding goes to education agencies in states and large cities and to national non-governmental organizations. CDC strongly recommends that HIV prevention be undertaken in the context of coordinated school health programs; more than 180,000 teachers each year are trained in the administration of such programs. This funding also helps grantees implement sound school HIV prevention policies, develop and disseminate HIV prevention curricula, and evaluate these prevention activities. Grantees are directed to work with the most at-risk populations.

The CDC's "Research to Classroom" project identifies curricula that have good evidence of reducing sexual risk behaviors in either classroom or community settings. In the last four years, new curricula have met the stringent scientific criteria CDC uses to assess prevention program effectiveness.

At this point, most students are learning at least something about HIV in school:

- ▶ There was an increase in the percentage of high school students who said they were taught about HIV/AIDS in school between 1995 and 1997 (from 86% to 92%).
- ▶ Many schools have established notable HIV education programs, but not all students are offered evidence-based HIV education. Increased access to these effective programs was a major theme in the last ONAP report. Local political constraints, limited coordination between school officials and health departments, and level funding have stood in the way of making evidence-based HIV education more widely available in schools.

None of the curricula on the current list of programs that work uses an “abstinence-only” approach, but the 1996 welfare legislation made available a total of \$250 million over five years to support programs that have “...as [their] exclusive purpose, teaching the social, psychological, and health gains to be realized by abstaining from sexual activity.” As previously noted, the effective programs identified to date provide information about safer sex, condoms, and contraceptives, in addition to encouraging abstinence.

Programs that put an even greater emphasis on abstinence or delay of sexual debut deserve further scientific study, and such studies are being supported by NIH, ASPE, CDC, and many states. However, it is a matter of grave concern that there is such a large incentive to adopt unproven abstinence-only approaches.

As important as effective school-based HIV prevention education is, it must be part of a mix that includes community-based programs. They enable youth who have dropped out of school or who attend infrequently to receive life-saving information through trusted channels, in convenient places, and in formats that have been tailored to their diverse needs.

We do not know enough about the extent and range of community-based services for high-risk youth. Many of these services are sponsored by private sector entities or funded by block grants that do not require reports back to the government about how funds were used. However, there is widespread agreement among those who work with and study young people that many high-risk youth are not being served.

Community-based programs often respond to the reality that HIV risk behavior does not occur in a vacuum. Young people have other pressing concerns (e.g., poverty, lack of adult mentoring, sexual abuse, sexual identity issues and drug and alcohol dependency) that must be addressed if they are to avoid unsafe sex.

### *Substance Abuse Treatment and Prevention*

For a number of reasons, drug and alcohol prevention and treatment are essential elements in the array of services needed to prevent HIV infection. Sharing equipment used to inject drugs is one of the leading sources of exposure to the HIV virus. Addiction can result in exchanging sex for drugs, a practice that carries major HIV risks. Again and again, youth who drink



heavily or use illegal drugs have been shown to engage in more risky sexual behavior than other young people. Even occasional substance abuse can impair judgment, making a young



person more susceptible to pressure to engage in unwanted or unprotected sex. Fortunately, communication and refusal skills acquired in a substance abuse prevention program can help a young person resist sexual pressure as well as pressure to take drugs.

In FY2000, the Substance Abuse and Mental Health Services Administration (SAMHSA) awarded \$1.6 billion to states through a Federal block grant program. This Federal funding represents about half of all public funding for substance abuse treatment and prevention programs. Funding for the block grant program has increased from just over \$1.2 billion since the 1996 ONAP report.

States with 10 or more cases of AIDS per 100,000 residents are required to “set aside” 5% of the funds from their Substance Abuse Prevention and Treatment (SAPT) block grants for early intervention services related to HIV. These services must encour-

age voluntary HIV counseling and testing among substance abusers and their sex partners, and provide clinical services to those who are HIV-infected.

In addition, the states that use part of their SAPT block grants for treatment for injection drug users (IDUs) are required to provide outreach services to IDUs. Designed to encourage entry into treatment, the outreach services are often based on indigenous leader and health education models. Fifty-seven percent of the states that provide IDU treatment recently reported that their outreach services target high-risk youth as well as adult populations.

Finally, SAMSHA funds a High Risk Youth Program which is administered from the agency’s national headquarters. This nationwide program develops and documents approaches to preventing drug and alcohol use among young people in high-risk environments, and disseminates the successful approaches. Examples include:

- ▶ Working with health department staff to make information and services relevant to HIV, STD, tuberculosis, and Hepatitis B and C accessible to adolescents in drug treatment in Tucson, Arizona.
- ▶ Placing emphasis on respect for heritage and tradition, relapse prevention, and breaking addictive cycles in chemical dependency and mental health treatment programs for hard-to-reach Native American youth in Alpine, California. Eligible youth are 12-18 years of age and come from families below the Federal poverty level. The program supports the individual, family and community in progress towards permanent recovery.
- ▶ Recruiting Newark, New Jersey adolescents at high risk of HIV and substance abuse for a teen theater company. Called “Teen-to-Teen,” the troupe writes and performs one-act plays for teen audiences. The plays deal with HIV and substance abuse prevention, unplanned pregnancy, child abuse, weapons and violence, and other issues important to teens. The company members

also join adult facilitators in co-leading small group workshops on topics such as conflict negotiation and dealing with peer pressure. Ninety percent of the company members have continued their educations beyond high school.

- ▶ Using peer outreach workers to establish *and maintain* contact with homeless minority youth in Bridgeport, Connecticut who are involved with the criminal justice system, practicing survival sex, and abusing drugs. The outreach workers accompany clients to service appointments, finding those that miss appointments. Prevention case managers, substance abuse counselors and mental health workers all provide client-centered services out of the same facility.

In 1999, the Minority AIDS Initiative significantly increased SAMHSA's funding for substance abuse prevention and treatment services for youth of color. But despite these and other initiatives by government and the private sector, the shortfall of youth-targeted, community-based services remains acute. As the last ONAP report emphasized, we need more widespread sharing of information about programs that work, more financial support for HIV prevention and related prevention education, more support for substance abuse and STD treatment programs, widespread replication of existing models with evidence of effectiveness, and more good new HIV prevention ideas.

### *New intervention models*

Over the last few years, there has been some Federal support for new types of HIV prevention programs. Promising new approaches include enhancing parent-teen communication, youth development and service learning programs, "safer schools" initiatives, multi-level interventions (e.g., programs that target students, their parents, and their teachers), and social marketing campaigns.

Social marketing—the use of media campaigns and other marketing strategies to influence behaviors and attitudes—has received a lot of attention because it has the potential to reach so many young people. For example:

- ▶ The National Institute on Drug Abuse distributed post cards containing science-based information on drug abuse and addiction in locations such as record stores, coffee shops, bars, movie theaters and gyms.
- ▶ CDC released radio and TV spots tailored for minority youth audiences to stations throughout the country as part of its Prevention Marketing Initiative (PMI). In 5 PMI demonstration cities, volunteer coalitions (including youth) planned and launched multi-channel youth-oriented social marketing campaigns that reached thousands. An eval-





uation at the Sacramento, California PMI site showed that, community-wide, a reduction in teen risk behavior was associated with exposure to the campaign.

- ▶ Six national organizations have been funded by CDC to mount HIV prevention communication campaigns targeting young people. For example, the National Council of Negro Women is conducting a national communication project focusing on young African American women.

In some of the newest social marketing work, campaigns are being designed to encourage high-risk individuals to get voluntary HIV counseling and testing, the first step on the road to adequate care.



- ▶ HIV-infected young people, most of whom are unaware that they are infected, are a key audience for targeted “Know Your Status” campaigns that CDC will soon launch.
- ▶ An emphasis on high-risk young people is part of National HIV Testing Day, a Federally-funded campaign organized by the National Association of People with AIDS. The campaign encourages youth who have engaged in risk behavior to learn their HIV status.
- ▶ With co-funding from Health Resources and Services Administration (HRSA) and private sources, the NIH Adolescent Medicine HIV/AIDS Research Network created Project ACCESS, a youth-oriented social marketing campaign to promote HIV counseling and testing. Using print, radio, and television ads, the project reaches young people with language and images that reflect youth culture. The project was pilot-tested in New York in 1997 and 1998. Project ACCESS is now expanding to Baltimore, the District of Columbia, Los Angeles, Miami, and Philadelphia with \$1.2 million from the HHS Minority AIDS Initiative.

Since 1996, Federal agencies have taken several other important steps to expand HIV counseling and testing for high-risk youth. For example, CDC is developing guidelines to help HIV test counselors respond to the unique needs of adolescents and young adults. The Food and Drug Administration (FDA) and CDC are working together to speed the approval of reliable HIV tests that provide immediate results, eliminating the time delay that has resulted in a failure to return for results. CDC also offers a course on youth-centered, client-focused prevention counseling.

Such activities should help young people learn their HIV status so that they can enter care, but the Federal resources devoted to this effort are still meager compared to the number of youth at risk of HIV infection. As the following section on care and treatment makes clear, much more remains to be done to provide developmentally appropriate, culturally competent HIV counseling and testing to all the young people who have engaged in HIV risk behaviors.

## CARE AND TREATMENT RESPONSE:

Early medical care and other supportive services are making it possible for some HIV-positive young people to live longer and to enjoy greater quality of life. Treating problems before they become serious may also reduce overall medical costs.

The Federal government provides care and support for young people living with HIV and AIDS through HIV-specific programs and health insurance coverage. Between 1996-1999, discretionary Federal spending on HIV-specific care and support programs increased from about \$1.4 billion to \$2.2 billion. In addition, each year almost one million 15-20 year olds receive Early Periodic Screening, Diagnosis and Treatment (EPSDT) exams through Medicaid. Finally, a new Federal initiative, the Children's Health Insurance Program, has made more adolescents eligible for health insurance coverage.

Despite this considerable investment, there are relatively few HIV-positive youth in care. In part, this is because many HIV-positive youth do not know that they are infected. Other barriers to health care access include remaining gaps in health insurance coverage, a shortage of health care providers with expertise in both HIV and adolescent medicine, and confidentiality concerns.

### *HIV Medical Care and Supportive Services*

The Ryan White CARE Act (RWCA) is the largest discretionary Federal program dedicated to HIV care and treatment. RWCA is administered by HRSA. Across the country, this program supports a wide range of community-based services including primary and home health care, access to medications, case management, mental health services, dental care, nutritional services, and linkage to substance abuse treatment and housing assistance. As the number of people requiring care has increased, RWCA has grown from a \$220.5 million program when it began in 1991 to a \$1.6 billion program today. Youth are eligible for all RWCA programs, which are targeted to specific populations on the basis of local needs assessments. Approximately 7% of the 500,000 clients served in Titles I, II, and III of RWCA (provisions authorizing grants to high-incidence cities, to states and territories, and to primary healthcare systems and community-based organizations) are young people between 13 and 24 years of age.

In addition, Title IV of RWCA funds sites to reach out to children, youth, women, and families and to provide them with comprehensive care. There are Title IV grantees in 27 states, Puerto Rico and the District of Columbia. From 1995 to 1997 alone, the number of young people ages 13-24 served by Title IV increased by 225%. Title IV projects have been most successful at reaching young women, one of the fastest-growing groups of HIV-infected individuals in the country.

The research and development arm of RWCA is its Special Projects of National Significance [SPNS]. Young people were the sole focus of ten SPNS awards made in 1994. HRSA awarded \$2.7 million in three-year grants to community-based organizations to develop and pilot-test innovative models of HIV care for adolescents and young adults. The projects explored various methods of outreach to HIV-positive youth and ways to increase early entry into primary care and support. In 1998, the findings of this first generation of adolescent demonstration projects were published. Some of the findings were that:

- ▶ HIV-positive adolescents in Indiana needed two case managers—one for social services and one for medical services. This level of service resulted in better physical health and in significant reductions in sexual and drug risk behaviors.

- ▶ Recreational activities helped retain youth in the care system. Staff in a program for substance-abusing youth in San Francisco had to become role models for having fun while clean and sober.
- ▶ Few at-risk girls in Birmingham, Alabama took advantage of SPNS services until the services were moved from clinic settings to community sites that were more familiar to the girls.
- ▶ At Children's Hospital in Los Angeles, treating SPNS youth in a primary health clinic for adolescents and young adults made it possible for them to sit in a waiting room without having anyone make assumptions about their HIV status.

One lesson from the first-generation SPNS projects was that youth infected through perinatal transmission have very different needs and concerns than those infected through sexual or drug use behaviors. Strategies for tailoring care for each of these two subgroups are among the topics being explored in three new adolescent SPNS projects that are still underway. To put SPNS findings into practice, HRSA established a \$2 million Adolescent Initiative within Title IV. In addition, special training is offered to staff of programs funded under the other provisions of RWCA.

Youth projects are still eligible to apply for SPNS grants, but there is no longer a SPNS component dedicated to adolescents and young people. The Adolescent Initiative, which represents a very small fraction of Federal AIDS care dollars, is now the only ongoing RWCA program specifically for youth. It has made small grants to youth programs in just four cities (Boston, Chicago, New Orleans, and San Francisco) and Puerto Rico.

Overall, the number of programs that integrate primary care, specialized HIV medical treatment, mental health services, case management, and other supportive services into 1-stop shops has grown somewhat since the 1996 report, as has the number of youth enrolled. But there is still a widespread need for replication of the service models that have succeeded in getting young people into life-saving care and keeping them there. Current treatments are extremely expensive and have demanding regimens. They can cause severe and sometimes disfiguring side effects, require intensive medical monitoring, and can stop working over time. All of these factors are of particular concern for youth, and services for young people should take these concerns into account. The demand for tailored care for young people will increase as treatments for HIV extend life and medical treatment becomes more complex.

### *Health Insurance*

Medical care costs incurred by some HIV-infected youth are covered by Medicaid and other Federal programs that help low-income people cover general medical expenses. Since the 1996 report, significant progress has been made in extending health insurance to adolescents:

- ▶ Since it began in 1997, the State Children's Health Insurance Program (SCHIP) has helped insure over 2 million children and adolescents under the age of 19 whose family incomes are too high to qualify for Medicaid but too low to afford private health insurance.
- ▶ However, an estimated 41% of uninsured children and adolescents live in families with incomes that are too high to qualify for most state SCHIP programs.



Although Medicaid and SCHIP programs have helped many teens, health insurance for young adults is still sorely lacking. SCHIP and other public health insurance programs typically limit coverage to youth under age 19. This constitutes a major gap in coverage.

## *Housing*

Beyond medical care, stable housing is one of the most important parts of the safety net for persons living with HIV and AIDS and their families. Youth who are homeless or who run away from home are at greater behavioral risk of HIV infection. Youth who are infected with HIV are more likely to be able to follow complex treatment regimens if they have a reliable address where they can be reached by care providers, a safe place to keep medications, refrigeration for drugs that require it, and other necessities that many of us take for granted.

- ▶ Federal funding for the Housing Opportunities for Persons with AIDS (HOPWA) program has increased every year since the last ONAP youth report, with an appropriation of \$232 million for FY2000. Administered by the Department of Housing and Urban Development (HUD), HOPWA funds enable states and localities to work with nonprofit partners to plan, operate and evaluate housing for persons with HIV and AIDS.
- ▶ FY2000 funds provide housing assistance to 53,625 persons and related supportive services to an additional 23,700 persons with HIV and AIDS and their family members. Roughly 17% of persons receiving housing assistance are under the age of 17 and 18% are between the ages of 18 and 30.



HOPWA Special Projects of National Significance are able to provide services beyond housing to infected and at-risk youth. For example, the Center for Children and Families in New York City sponsors aggressive street outreach, specialized youth counseling, life skills training and other services at a drop-in center and a transitional housing program. The Center also provides technical support to over 100 local agencies and nonprofits that serve youth.

## **RESEARCH RESPONSE:**

The Federal government supports AIDS research in a wide range of scientific areas. They include natural history, epidemiology, behavioral science, basic biomedical sciences, therapeutics and vaccine discovery, development and testing, health services, and social science. This portfolio resides in numerous Federal agencies. Within the Department of Health and Human Services, NIH, CDC, HRSA, and the Agency for Healthcare Research and Quality support most of the research; the Department of Veterans Affairs and the Department of Defense also contribute to the AIDS research effort. These agencies have internal research planning processes and bring in outside experts to help set research planning priorities. The agencies use scientific conferences and journals and other mechanisms to disseminate research findings to a variety of audiences (e.g., scientists, policy makers, local service providers, and the general public).

According to the Office on Management and Budget, Federal spending on AIDS research programs has grown from approximately \$1.5 billion in FY 1996 to \$2.1 billion in FY 2000. Basic biomedical research (e.g., the studies that led to the identification of the HIV virus and an understanding of how it destroys the immune system) represents about half of this research portfolio. In most cases, basic biomedical research is not specific to young people, but it is critical to the development and evaluation of preventive measures and medical treatments from which young people stand to benefit. Although we acknowledge the central importance of basic biomedical research, it will not be described here. Instead, this report will highlight some prevention and treatment research that focuses on young people directly.

The NIH supports the majority of Federally-sponsored AIDS research and, in FY2000, targeted approximately \$60 million specifically to HIV/AIDS research with adolescents. Youth-focused HIV research is describing the extent of the HIV epidemic among young people, identifying effective HIV prevention approaches, revealing the effects of HIV disease in young people, and improving treatment regimens. In addition, NIH supports a large program of AIDS research with other groups (e.g., racial and ethnic minorities and pediatric populations) and on vaccine candidates and new treatments, and there are some young participants in this research. The agency also supports studies of adolescent sexual behavior that have direct implications for HIV research and practice.

Conducting the research necessary to further understanding, prevention, and treatment of HIV and AIDS in adolescents and young adults is an explicit priority for NIH and other Federal agencies. Funding for research on youth and AIDS has increased over the last four years, and we have learned a great deal, but we have not met all of the research challenges identified in the 1996 ONAP report (*see Attachment B*). Additional funding is needed to take advantage of research opportunities and to fill in knowledge gaps.

### *Prevention research*

Over 20 adolescent-specific studies funded by NIH are currently examining factors that lead to HIV risk behaviors. In addition, more than two dozen NIH-funded studies are developing and evaluating social and behavioral interventions to reduce HIV infections among youth. For example:

- ▶ The National Institute of Mental Health (NIMH) is studying ways to delay initiation of sexual activity and promote consistent practice of HIV risk-reduction behaviors. These include studies of adolescents recruited from STD and family planning clinics, residential settings, and school- and community-based programs. Interventions that involve parents and other family members in HIV prevention are being developed and evaluated. NIMH currently emphasizes studies on homeless and runaway youth, youth of color, and gay youth.
- ▶ The National Institute on Drug Abuse (NIDA) is supporting a study on the relationship between substance use and HIV risk behaviors among



homeless adolescents. It is also funding studies on HIV risks among young women who are injection drug users or sexual partners of injection drug users, and risk reduction interventions for drug-abusing juveniles admitted to court-mandated treatment.

- ▶ The National Institute of Nursing Research (NINR) is supporting several studies on behavioral interventions for youth, especially youth of color. For example, a University of Washington study is examining disease prevention beliefs and behaviors related to HIV and STD infections among Pacific Islander adolescents. Results will be used to develop and test a culturally sensitive adolescent health and HIV prevention program.
- ▶ The National Institute of Child Health and Human Development (NICHD) is studying HIV-positive youth and is combining medical monitoring with a prevention intervention. Another set of NICHD projects is investigating risk behaviors in middle childhood that might lead to risky sexual behavior later on; researchers will follow the children until some are 24 years of age. NICHD is also investigating the ways in which attitudes and sexual behaviors are influenced by romantic relationships. Youth in foster homes and other high-risk situations are participants in additional studies.
- ▶ Targeting HIV-positive individuals with the goal of helping them avoid transmitting the virus is an increasingly important focus of prevention research. For example, NIDA is supporting a study that is looking for ways to reduce substance use and risk behaviors, increase health care utilization, and enhance quality of life for substance-abusing youth living with HIV.

Several institutes at NIH co-support the NIAID-sponsored HIV Prevention Trials Network. It conducts domestic and international research on promising biomedical and behavioral strategies for preventing HIV transmission among adult, pediatric and adolescent populations. Among the types of interventions studied in this network are behavioral interventions, vaccines, and physical and chemical barriers (e.g., microbicides). Additional studies of these types of interventions are supported through NIH-sponsored programs elsewhere in the agency. The successful development of these HIV prevention tools will be invaluable to young people.

NIH advisory groups have determined that more research is needed to address HIV prevention-relevant scientific questions such as:

- ▶ What influences do family, social and sexual networks have on youth risk behaviors?
- ▶ There are different approaches to HIV prevention for young people, including STD treatment, promotion of barrier methods such as condoms, and communication and refusal skills training. Promotion of microbicides will be added to the list when these products become available. How should these approaches be combined?
- ▶ What are the essential ingredients in successful prevention strategies for youth?
- ▶ How should “essential ingredient” information be communicated to service providers who are tailoring standard prevention programs for particular populations of young people?

CDC and SAMHSA also conduct HIV/AIDS prevention research. Among their current projects targeting youth are:

- ▶ Project SHIELD, a community-focused program that is developing and evaluating ways to reduce high-risk behaviors [SAMHSA].
- ▶ The Community Intervention Trial for Youth (CITY), which is developing and evaluating a comprehensive, community-level approach to encourage young men who have sex with men to reduce HIV risk behaviors. Young men of color are the primary target audience [CDC].
- ▶ Project START (STD and AIDS Reduction Trial), which is developing and evaluating innovative methods to prevent HIV and STD infection and transmission among young men in prison who are about to return to their communities [CDC].
- ▶ Teen pregnancy prevention coalitions in four cities have been funded to develop and test strategies for integrating HIV, STD and pregnancy prevention messages for minority youth [CDC].

### *Treatment research*

NIH funds the majority of the research relevant to treatment for HIV and AIDS. The agency supports several research networks that conduct HIV/AIDS treatment research involving young participants, including the Pediatric AIDS Clinical Trials Group (PACTG), the Adult AIDS Clinical Trials Group (AACTG), the Community Programs for Clinical Research on AIDS (CPCRA), and the Adolescent Medicine HIV/AIDS Research Network (AMHARN). These networks evaluate antiretroviral treatments, medications for HIV-related opportunistic infections and malignancies, and medication regimens.

All the networks have begun to address the issues of simplifying treatment regimens for adolescents and recruiting and retaining youth in clinical trials. Recruiting young people into clinical trials remains difficult, and the concerns that young people have about participation may not be sufficiently understood.

Institutional review boards (IRBs) are standing committees at universities, hospitals, and other institutions that conduct research. IRBs examine research proposals to ensure that issues such as participant safety, confidentiality, and informed consent have been adequately addressed. IRBs must follow Federal regulations (promulgated by NIH) and state and local laws that protect minors as a special population. However, the potential value of information about young people should also be heavily weighted in IRB deliberations.

In 1994, the AMHARN was established by NIH to create an infrastructure for AIDS research specifically targeting adolescents ages 13 to 19. AMHARN's objectives are to: characterize the natural history of HIV in adolescents; study basic science questions about the susceptibility, infectivity, and transmissibility of HIV in adolescents; produce clinical management guidelines for adolescent HIV infection; and provide youth access to clinical trials. Two major Network initiatives are Project REACH and Project TREAT.

- ▶ Project REACH is an observational study of the biomedical, psychosocial, and behavioral aspects of HIV infection in adolescents. The project has enrolled approximately 350 HIV-positive youth and 180 HIV-negative high-risk youth at 15 clinical sites across the country. REACH has already yielded much of what is known about adolescent-specific responses to HIV infection.
- ▶ Project TREAT is a new effort to help adolescents participate effectively in complex treatment regimens. Project TREAT is developing, evaluating, and distributing a multi-faceted program intended to enhance treatment adherence. The project has produced a monograph on adherence support for clinicians treating HIV-positive adolescents.



HRSA (see the description of SPNS in the section on HIV Medical Care and Supportive Services) and CDC also conduct treatment-relevant research. Two large ongoing studies at CDC focus on children who were infected perinatally and are now adolescents. A new CDC study of HIV-infected adolescents will examine the continuity of care provided by HIV specialists, adherence to medical regimens, and strategies for preventing further HIV transmission.

The HIV/AIDS epidemic among our nation's youth demands increased scientific attention and a more efficient two-way information pipeline between scientists and those on the front lines of the battle against AIDS. Collaborative ground has been broken. Scientists and service providers are research partners in many studies around the country, and some mechanisms for dissemination of scientific information are in place. However, optimal information exchange will require new strategies for collaboration among Federal agencies and between researchers and practitioners.