



Youth and HIV/AIDS 2000:

A New American Agenda

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Table of Contents |

v		Summary
vii		A Message from the Director of National AIDS Policy
1		Findings
1		<i>The Problem</i>
13		<i>The Response</i>
27		Recommendations
35		Conclusion
37		References
39		Attachment A: Acknowledgements
41		Attachment B: Recommendations from the 1996 ONAP Report
43		Attachment C: Glossary

1. AIDS is not over. Scientists believe that there have been 40,000 new HIV infections in the United States every year for the last several years, and that half of those being infected are young people between the ages of 13 and 24.
2. Most young people who are already HIV-infected don't know it.
3. The vast majority of HIV-infected youth do not receive adequate medical care.
4. For many young people infected with HIV, new medical treatments could lead to long, productive lives. To make this a reality, they need youth-friendly access to HIV counseling and testing, medical care (including mental health care), and other support services.
5. The best treatments fall far short of a cure and we have no vaccine. Behavior change is still the key to preventing HIV and protecting America's youth.
6. Prevention science has identified programs that can reduce risk behavior, but these programs are not offered in most schools and communities. Some of the proven programs were designed for small group or classroom use. With an emphasis on communication, negotiation and refusal skills, they state clearly that abstinence is important, and also provide information about condoms and other contraceptives. Other effective programs offer individualized counseling to high-risk youth, or use outreach workers to deliver prevention messages. A final group of programs mentor young people in activities that make the future seem brighter and staying safe seem worthwhile.
7. We still need answers to major questions about preventing and treating HIV and AIDS in young people. For example, we need to know how medical treatments for HIV affect a person who is still developing physically.
8. All young people need the tools to protect themselves from AIDS. The youth at highest risk of HIV infection need additional help. They are confronted with poverty, racism, sexism and homophobia. Many are out of school, lack access to health care, and are exploited by adults. Youth at highest risk urgently need school and community-based prevention programs that address all the daunting challenges they face.
9. Important parts of a comprehensive prevention/care system are now in place. There is more to learn, but we know enough now to tie key parts of the system together and extend it to cover all of our youth. This will take more resources, and more strategic use of existing resources. Working together, we can provide proper care to youth with HIV and AIDS, and we can turn the tide against new HIV infections in young people.

"It's nasty to talk about it. But if we mess up, we could get HIV. When are they going to start talking to us? We shouldn't have to do this alone."

*17 year old Latina girl,
California*

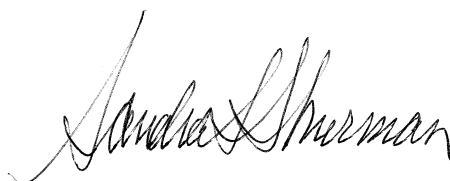
September, 2000

Alarmed at the threat HIV posed to America's young people, the Office of National AIDS Policy (ONAP) issued a wake-up call to the nation in a 1996 report, *Youth and HIV/AIDS: An American Agenda*. Americans under age 25 were becoming infected with HIV at the rate of two per hour, and the report named them a "generation at risk." Today, we report again on the status of the epidemic among young people, acknowledging progress made and calling for a reinvigorated national response to the problem.

The past four years have brought major advances and many young people have benefited from this success. New medical treatments have dramatically reduced AIDS death rates. We have also learned important lessons about preventing risk behavior and about providing youth-friendly services to the young people who are already HIV-infected. We now have strategies for bringing young people into scientific studies and for getting science out to practitioners who can put it to work for young people.

This good news is a return on our national investment in AIDS, but the good news is only part of the story. It is deeply distressing that the number of young people becoming infected has remained constant year after year and that most HIV-infected American youth are not receiving adequate medical care. Hard work and commitment have produced many of the tools we need for a successful campaign against HIV and AIDS in young people. While this innovation continues, we must move from paper to practice by putting what we already know to work for all young Americans. The time to act is now.

With the release of this report: *Youth and HIV/AIDS 2000: A New American Agenda*, we urge government at all levels, the private sector, parents, schools, community based organizations, religious institutions, concerned individuals and young people themselves to join forces in a renewed commitment to fighting HIV and AIDS in our nation's youth. Young people are our most valuable resource — our best hope for the future. The lessons we learn along the way will serve the entire global community.



Sandra L. Thurman

Presidential Envoy for AIDS Cooperation and
Director, Office of National AIDS Policy

Findings

THE PROBLEM:

Our best estimate is that *young Americans between the ages of 13-24 are still contracting HIV at the rate of 2 per hour.*

The AIDS epidemic is not over, and young people in the U.S. are not immune.

- ▶ Half of all new HIV infections are thought to occur in young people under 25.
- ▶ More than 123,000¹ young adults in the United States have developed AIDS in their twenties. The delay between HIV infection and the onset of AIDS means that most of these young people were infected with HIV as teenagers.
- ▶ The total number of youth in the U.S. who have been infected with HIV is unknown, but public health officials believe that 20,000 people between 13 and 24 years of age are infected with HIV every year.

Millions of American youth are still engaging in sexual behaviors that put them at risk for HIV/AIDS.

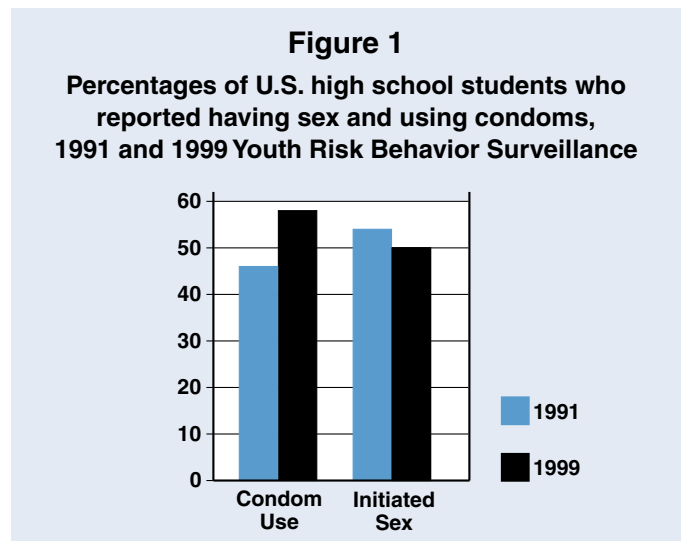
- ▶ HIV infection is usually contracted sexually among young people.
- ▶ By 12th grade, 65% of American youth are sexually active, and one in five has had four or more sexual partners.
- ▶ Each year, three million adolescents contract sexually transmitted diseases (STDs). That's about one in four sexually experienced teens. Of the 12 million Americans with STDs, about two-thirds are young people under age 25. These statistics indicate that many adolescents are engaged in unprotected sex—behavior that places them at risk of HIV infection.



Fortunately, there has been a drop in sexual risk behaviors and an increase in condom use among sexually active high school students.

¹All HIV and AIDS case statistics cited in this report are drawn from the most recent surveillance data from the Centers for Disease Control and Prevention (CDC); the reporting period extended through the end of 1999. This was also the most recent year that high school students' risk behavior was surveyed.

The percentage of high school students who say they have had sexual intercourse decreased from 54% in 1991 to 50% in 1999. The percentage of sexually active high school students who say they used a condom the last time they had sex increased from 46% to 58% during the same period (*see Figure 1*). Their accounts were confirmed when, in 1999, births to teenagers fell to their lowest rate in 60 years.



Still, the number of young people having unprotected sex remains perilously high, and trends in risk behavior among some groups of youth are not as encouraging as those from regular high schools. Alternative high school youth, college students, sexual minority youth, and Native American youth have all reported higher rates of unprotected sex. Without expanded prevention efforts with these groups, their rates of HIV infection are likely to rise.

The abuse of alcohol and other substances also contributes to HIV risk in young people. It can impair judgment in sexual situations and can involve sharing injection equipment, a direct means of HIV exposure.



- ▶ Twenty-five per cent of U.S. high school students who have had sex said they were under the influence of alcohol or drugs (including marijuana and other illegal drugs, prescription drugs, and low-cost inhalants like gasoline, spray paint and glue) the last time they had sex.
- ▶ Binge drinking was recently reported by 31% of high school students. Among young people contacted at home, 38% of those 18-25 years old and almost 46% of those 21 years old reported binge drinking. The definition of binge drinking is having at least 5 drinks on the same occasion within the last month.

- ▶ An estimated 1.5 million Americans are current cocaine users, and about half of them are age 25 or younger. The use of crack has more than doubled among those 12-17 since 1991.
- ▶ About one in 50 high school juniors and seniors admitted injecting illegal drugs.
- ▶ There is a normal tendency for young people to take risks. Those who engage in one risky behavior often engage in others. Young people who drink or use drugs are much more likely to have sex. On the other hand, those with the social skills to refuse unwanted or unprotected sex are also better able to refuse drugs.

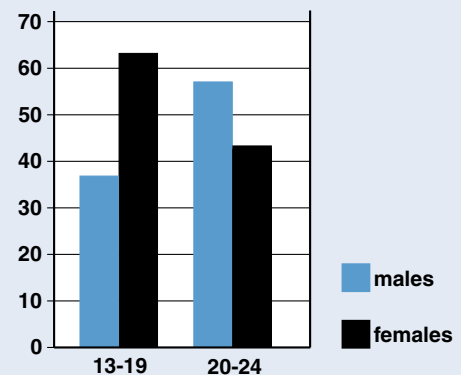
Some young people are in even greater jeopardy.

Any young person who engages in HIV risk behavior could become infected, but the epidemic has taken an especially heavy toll in certain groups of youth. Young women—particularly young women of color—and young men who have sex with men have been hit very hard by the epidemic.

Young women

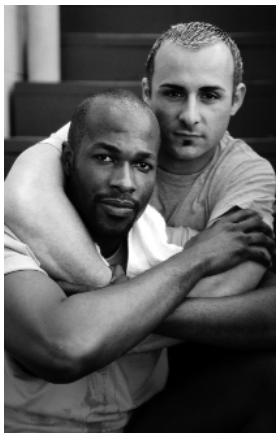
- ▶ More females than males are now being diagnosed with HIV in the 13-19 year old age group (*see Figure 2*). In this group, 63% of the 828 HIV infections reported last year were among females. In the next oldest group, 20-24 year olds, women represent about 44% of the 2,386 HIV infections reported in 1999.
- ▶ In disadvantaged youth entering the Job Corps, young women from the South and Northeast had the highest HIV infection rates of all. Prevalences of up to 1 per 100 were found, with the highest rates in the District of Columbia, Florida, Louisiana, Maryland, South Carolina, Virginia and Connecticut.

Figure 2
Percentages of HIV cases reported in 1999 among males and females in the 13-19 and 20-24 year old age groups²



² HIV data are reported by 33 states (not including California and New York) and the U.S. Virgin Islands.

Young men who have sex with men

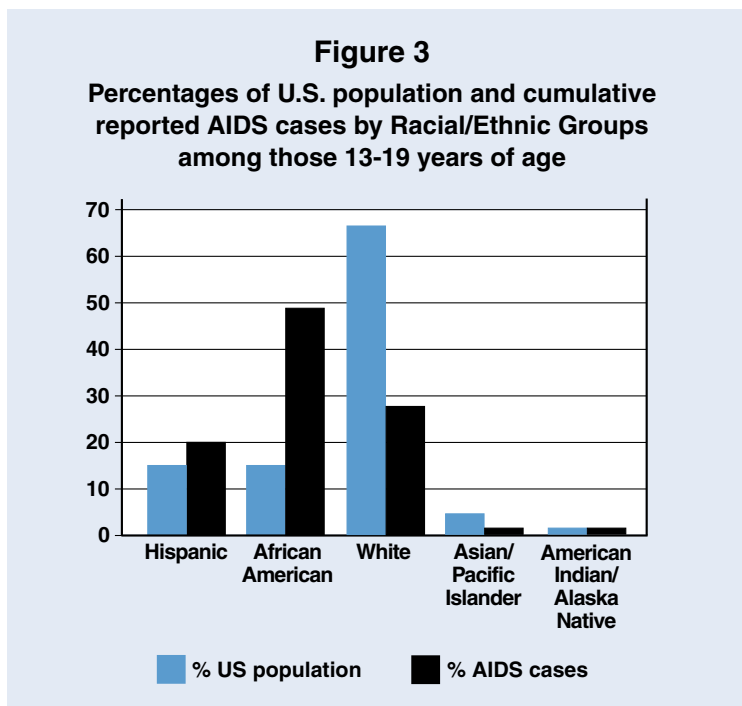


- ▶ At least half of the HIV infections reported last year among young men aged 13-24 resulted from exposure to the virus through sex with other men.
- ▶ A recent seven-city survey of 3,492 men ages 15-22 who have sex with men found that, in the last six months, 41% had engaged in unprotected anal sex, an especially high-risk activity.
- ▶ Young urban men who have sex with men show alarming rates of HIV infection—just over 7%—with higher rates among African Americans, Latinos, and those of mixed race than among whites.

Minority youth

African American and Latino youth continue to be disproportionately affected by HIV and AIDS.

- ▶ African Americans and Hispanics each make up about 15% of U.S. teenagers. However, African Americans account for 49% of the 3,725 AIDS cases ever reported among those aged 13-19, and 67% of the 4,796 HIV infections reported to date in this age group. Hispanics represent 20% of AIDS cases among teens (*see Figure 3*).



- ▶ There is a racial/ethnic disparity in the next oldest age group as well. Of the 25,904 cases of AIDS reported so far among those ages 20-24, people from racial or ethnic minority groups account for about 65%. Young women of color account for 78% of the AIDS cases among young women.
- ▶ For youth entering Jobs Corps, HIV infection rates were 7 times higher among African Americans than among their white counterparts.

Youth in high-risk situations

Youth who drop out of school, are sexually abused, run away from home, are incarcerated, are in other out-of-home residential placements, or are homeless remain at high risk for HIV and AIDS.

- ▶ About 4 million young people (12% of those ages 16-24 in the United States) are not enrolled in a high school program and have not completed high school. Compared with youth in school, out-of-school youth are significantly more likely to have had sex, to have had more than 4 sex partners, and to have failed to use a condom the last time they had sex.

- ▶ In 1998, there were more than 2.6 million arrests of youth under age 18. Over 100,000 juvenile offenders are in residential placement (e.g., jail, juvenile detention centers) on a typical day. Compared with other youth, youth in detention have engaged in much more HIV risk behavior, but they know less about HIV.
- ▶ Estimates of the number of homeless and runaway youth range from 730,000 to 1.3 million. Many of these young people use injection and other drugs and exchange sex for money, food, or shelter. One study of homeless youth in four cities found a median HIV infection rate of 2.3%. Some studies have reported rates above 10%.



Like adults in this country, America's young people may be growing complacent about AIDS.

"AIDS is kind of like school violence. You're like, 'it can't happen to me, it can't happen at our school,' and that's the attitude..."

*Adolescent Health Clinic Client,
Montefiore Hospital, New York City*

Although most young people see AIDS as a major social problem and know the basics about how to protect themselves from HIV, they tend not to think that they are personally at risk.

- ▶ In a recent survey, 87% of young Americans said they do not believe that they are at risk for HIV infection. This impression can be tragically mistaken, and it can undercut the motivation to avoid sex or use condoms.
- ▶ Unrealistic expectations about the effects of medical treatments for HIV and lack of hope for a rewarding future can also contribute to a young person's complacency about HIV prevention.

Proven HIV prevention models have not been widely adopted.

Almost all states have policies that support HIV prevention in schools, but local communities generally make their own decisions about curricula. There is credible evidence that several prevention programs that are appropriate for classroom use can lower HIV risk behavior among young people (*see the box on Programs That Work, page 6*), but many school districts have chosen *not* to adopt these evidence-based programs.

There also continues to be a very dangerous dearth of prevention services for high-risk youth who don't attend school regularly, who drop out of school, who have been incarcerated or placed in some other out-of-home residential setting such as foster care, or who are homeless. Again, there are effective community-based models. Numerous programs are underway around the country, but the unmet need remains striking.

Programs that Work

The National Institutes of Health (NIH), CDC, and other Federal agencies fund well-designed evaluations of HIV prevention programs, and the results of many of these studies are published in the scientific literature. CDC identifies effective programs so that they can be drawn to the attention of prevention service providers.

To qualify as effective in one ongoing literature review, a program must be intended for school-aged youth, have a curriculum that is a complete set of procedures appropriate for classroom or other small group use, have an evaluation published in a peer-reviewed scientific journal, and show scientifically credible evidence of reducing sexual risk behavior without increasing sexual behavior. Five "Programs That Work" have been identified by this review to date; three target minority youth. Two were designed for both middle school and high school-aged youth, and three were developed for high school-aged youth only. All involve several hours of instruction and supervised activity. They not only teach facts about HIV and its prevention, but also help develop communication, negotiation, and refusal skills. They are interactive, offering opportunities for practicing interpersonal skills and for group discussion. CDC posts fact sheets about these programs on the web

(<http://www.cdc.gov/nccdphp/dash/rtc/index.htm>). In the first year after a new program meets 'Programs that Work' criteria, there are usually two national trainings on its procedures. After that, the curriculum publisher and state education agencies sponsor additional trainings.



Another ongoing review, the HIV/AIDS Prevention Research Synthesis (PRS) Project, identifies programs that have worked to reduce sex or drug-related risk among either young people or adults. In addition to reviewing evaluations of programs suitable for small groups, PRS examines research

on programs that used other means to deliver prevention messages such as peer and street outreach, individualized counseling, distribution of localized print materials, and multiple strategies in various combinations. Programs that qualify are described in the "Compendium of Effective Interventions to Reduce HIV" which is also available on the web (<http://www.cdc.gov/hiv/projects/rep/compend.htm>). Training in these program procedures will soon be offered at four regional training centers. Materials and scripts used in the effective programs are being packaged for easy replication by CDC and NIH.

School-based programs

- ▶ Youth at high risk of HIV infection are often still in school and eighty per cent of junior and senior high schools include HIV prevention as a topic in a required course. However, only 33% of the teachers who considered HIV a major topic in their courses discussed the correct use of condoms.
- ▶ In that survey, only 31% of teachers reported receiving training on HIV-prevention in the previous two years.
- ▶ The shortest of the small group-based prevention “programs that work” with adolescents is five one-hour sessions long. Almost 50% of teachers who teach about HIV reported spending only one or two class periods on the topic.
- ▶ In surveys conducted in high schools in Boston and the state of Vermont, 3%-5% of students reported same sex activity. There are programs that work for gay youth, but few schools have made such programs available to students.
- ▶ There is limited Federal funding to support STD education in schools.

Community-based programs

- ▶ Young people between 13 and 24 constitute only 16% of the population at large. With an estimated 50% of new HIV infections, they are heavily over-represented in projected statistics. Nonetheless, only 25 of the 120 community planning groups charged with setting priorities for local use of Federal HIV prevention funds identified youth as a priority target audience.
- ▶ Organizations that provide support for gay youth exist in only 33 states and the District of Columbia; most of these groups provide services only in one or two major cities.
- ▶ Promising models are emerging for integrating HIV prevention into juvenile justice settings and other venues that serve youth in high-risk situations. Relevant technical assistance is available from several national non-governmental organizations, and many community-based organizations and health departments target this population. Still, most experts agree that there is a very large unmet need for community-based HIV prevention services for youth in high-risk situations.

More research on creative prevention models could identify effective new approaches.

“My parents bring it up because they know that they should, but they don’t know what to say. So they’re like, Do you have any questions? Anything you want to know? No? Well, it’s good that we talked.”

Teen focus group participant, Parent HIV education program, Ithaca, New York

- ▶ Programs that help parents communicate with their children about HIV may lower youth risk behavior. The first data on this kind of program outcome are only now being collected.
- ▶ Youth development programs (*see A Shift in Approach: Positive Youth Development*) range from late-night sports teams to computer clubhouses. They are becoming increasingly widespread and they often bring to bear private sector resources that could make a big difference for at-risk youth. Unfortunately, few of these programs have been rigorously evaluated. The ones that are community-based have received less attention than the ones with activities in schools.

A Shift in Approach: Positive Youth Development

A successful transition to adulthood involves more than avoiding drugs, violence and risky sexual activity. Instead of focussing on problem behaviors, some new prevention programs are helping create circumstances that foster resilience. Called “youth development” programs, these approaches were the subject of a recent review sponsored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the Department of Health and Human Services (DHHS). In the review, a program was considered effective if there was scientifically credible evidence that it increased positive behaviors like academic achievement and/or decreased risk behaviors.



The effective programs: (1) built competencies and self-efficacy (the belief that trying will result in success), (2) helped families and communities send consistent messages about standards for positive behavior, (3) expanded opportunities and recognition for youth who engage in positive behavior and activities, (4) provided structure and consistency in program activities, and (5) lasted at least 9 months. Two-thirds of the successful programs used the combined human resources of families, communities, and schools, thus increasing an adolescent's sources of contact with healthy adult role models.

The Seattle Social Development Project combined “Catch ‘em Being Good” parent training with training for teachers in proactive classroom management, interactive teaching, and cooperative learning methods. When students were in 6th grade, they learned to resist peer influences to engage in problem behavior and to think of positive activities that would keep them out of trouble. Six years later, compared with similar students who did not participate in the program, fewer program students had had sex. Those who had started to have sex had had fewer sexual partners.

Another program, “Teen Outreach,” was sponsored by a private-sector women's group. It got high-risk high school girls involved in volunteer work. The girls also received social competence training in classrooms. One year later, they were less likely than non-participants to have gotten pregnant, to have failed in school, or to have been suspended.

- ▶ There is a chronic lack of coordination of youth services and programs with related content (e.g., HIV prevention, pregnancy prevention, STD prevention, and drug prevention and treatment). This lack is evident within Federal agencies, between Federal agencies, and at the state and local levels. Research is needed to identify models of effective service coordination.

Treating other STDs and drug abuse reduces the risk of HIV infection, but youth face a shortage of both types of treatment.

- ▶ STD treatment reduces the risk of HIV infection by healing open sores or lesions, and an STD diagnosis constitutes a powerful “teachable moment” for HIV prevention. Nonetheless, STD screening and treatment services are underfunded. For example, in the country’s most populated areas, chlamydia screening reaches only 20% of the young women in need.
- ▶ Dependency on illicit drugs or alcohol was reported by approximately 1.3 million people between 12-17 years of age who responded to a national household survey in 1999. In the same survey, responses from those ages 18-25 indicated that 3.4 million were drug or alcohol dependent.
- ▶ By contrast, only 296,000 of those in the 12-17 year age range and 561,000 of those 18-25 years old reported receiving substance abuse treatment. Many drug treatment facilities have waiting lists.



Most young people who are HIV-infected don’t know it.

- ▶ Millions of young people who have engaged in high-risk behaviors do not know their HIV status. There are an estimated 250,000 Americans who unaware that they are HIV-infected, and many of them are young people.
- ▶ A person who is HIV-infected must know it in order to take advantage of promising new treatments for HIV. In a recent survey of young men who have sex with men, 249 were found to be HIV positive. Only 18% of them knew they were infected before the survey, and only 15% of them were receiving medical care.
- ▶ Research has shown that knowing one’s positive HIV test results brings about significant reductions in risk behavior, avoiding transmission of the virus to others.

Young people who have had unprotected sex or who have shared needles should be encouraged to seek voluntary HIV counseling and testing. If the test result is positive, they should be linked to a comprehensive system of care. If the result is negative, they should receive HIV prevention counseling.

Young people face many barriers to HIV counseling and testing.

The prospect of getting a positive HIV test can be overwhelming. In addition, there are practical barriers to learning your HIV status if you are a young person in the United States.

- ▶ Many youth at risk of HIV infection have no doctor or other health care provider to turn to for advice.
- ▶ Young people may not know how or where to get an HIV test. Even if they know where to go, there are still logistical problems. For example, some counseling and testing facilities are open primarily during school hours, and some sites offer counseling in English only.

*“I think some teens are
afraid to get tested
because they think their
parents are going to
find out.”*

*Second Baptist Church
Youth Group Member,
Fairfax, Virginia*

- ▶ Some young people are under the false impression that they are tested for HIV during routine medical exams (e.g., gynecological check-ups), and they assume that they would be notified if they tested positive.
- ▶ Parental consent is not required for HIV testing, but some teens avoid testing because of doubts about the confidentiality of their test results. These doubts are often warranted; some states allow parental notification of a positive test result at the physician's discretion, and one state requires parental notification.
- ▶ Reliable HIV tests that provide immediate results (so-called rapid tests) are not yet licensed and on the market. Young people who do manage to overcome initial barriers to HIV testing often fail to return for test results that take more than a week to become available.

HIV counseling and testing help a young person most when these services are tailored to his or her mental and emotional state, language, culture, and sexual orientation. There are too few youth-friendly testing sites. Special training can equip staff to work with young people in a supportive way that accommodates their unique needs.

HIV-infected youth are not receiving the health care they need to live as long and as productively as possible.

Because most young Americans with HIV infection don't know they are infected, they can't receive proper medical care, even when it is available. In fact, many young people find out they are infected only after they become seriously ill, too late to benefit from early treatment. Those that learn that they are HIV-positive may not have access to adequate care. Compared with children and older adults, young people are much less likely to have medical insurance. Those who are insured may not be covered for some key services such as mental health care. On top of that, many of those who are insured have trouble finding health care providers who are experienced with youth and who also know a lot about HIV. For young people who live in small, rural communities, it can be very hard to find appropriate services close to home and confidentiality concerns are often heightened.



- ▶ One study estimated that only 11% of youth living with HIV in the United States receive adequate medical care.
- ▶ Roughly one in three 18-24 year olds has neither public nor private health insurance, and the number of uninsured continues to climb each year.
- ▶ In 1997, low-income people aged 19-20 had the highest uninsured rate of all groups — 47.7%.
- ▶ The largest gaps in medical services for youth are in substance abuse and mental health services, both of which are central to the needs of many HIV-infected and at-risk youth.

Biomedical research has led to great strides in HIV/AIDS treatment, but much remains to be learned about the progression and treatment of the disease in adolescents.

- ▶ New treatments have produced dramatic reductions in the number of deaths from AIDS. Among those 15-24 years of age, the number of deaths in 1998 was 53% less than in 1996.
- ▶ Too few adolescents have participated in medical research to allow confidence that they will react to AIDS medications and dosages the same way adults do. Clinical research with HIV-infected youth is hampered by the small number of HIV-positive youth receiving care, and by the unique challenges of recruiting and retaining adolescent research participants.
- ▶ The systems for conducting medical research for HIV-positive youth are newer and less developed than those for children and adults. Young people also continue to make up a very small percentage of participants in clinical studies that are not youth-specific (e.g., vaccine trials). Young HIV-positive people are the best potential source of guidance in recruiting their peers and keeping them involved.



In many cases, the findings just described echo the findings about the status of American youth and HIV that were listed in the 1996 ONAP report (*see Attachment B*). The following section of this report describes the Federal response to these complex, persistent issues with an emphasis on action taken during the last four years. It is not possible to list here all of the activities carried out during this period by any Federal agency, but an attempt has been made to include the major ones.