While every sexually active teenager is at risk for contracting the Human Immunodeficiency Virus (HIV), some have been found to be at higher risk because of behavioral, socioeconomic, or environmental factors. These youth include: runaway and homeless youth, detained or incarcerated teens, alcohol- and other drug-using youth and their sexual partners, out-of-school youth, adolescents in rural communities, gay youth, immigrant youth, survivors of childhood sexual abuse, and African-American and Hispanic youth. A analysis of successful prevention programs yielded 11 program components that should be part of effective HIV/AIDS programs. The two most widely applicable are intensive, individualized attention and community-wide, multi-agency approaches; others include early identification and intervention, social skills training, and parental involvement. Six major considerations for prevention programs are: (1) no single program component can alter the outcomes for all children at risk; (2) high-risk behaviors are interrelated and prevention programs should have holistic goals; (3) a package of services is required within each community; (4) interventions should be aimed at changing institutions; (5) early intervention is crucial; and (6) one-shot programs have no effect. Three model HIV/AIDS prevention programs for high risk young people are highlighted and six policy recommendations for establishing effective programs are offered. (Contains 36 references.) (ND)
"ADOLESCENTS AND THE HIV/AIDS EPIDEMIC:
STEMMING THE TIDE"

APRIL 1993

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The Women’s NETWORK of the National Conference of State Legislatures (NCSL) represents the women serving in state legislatures across the country. The mission of the NETWORK is to offer effectiveness and leadership training to women legislators so they can realize their full legislative potential. Realizing that women’s issues are the responsibility of all legislators, it is the purpose of the NETWORK to develop and to influence public policy priorities for NCSL.

Chair: Senator Paula Hollinger, Maryland
Executive Director: Sue Mullins

The National Conference of State Legislatures serves the legislators and staffs of the nation’s 50 states, its commonwealths and territories.

NCSL was created in January 1975 from the merger of three organizations that served or represented state legislatures. NCSL is a nonpartisan organization with three objectives:

- To improve the quality and effectiveness of state legislatures;
- To foster interstate communication and cooperation;
- To ensure states a strong, cohesive voice in the federal system.

The Conference has offices in Denver, Colorado, and Washington, D.C.

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Adolescents and the HIV/AIDS Epidemic: Stemming the Tide

By Susan A. Messina

April 1993
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The Women's NETWORK is a nonprofit member organization affiliated with the National Conference of State Legislatures. NETWORK's goals are threefold: to increase and strengthen women's leadership within NCSL; to increase and strengthen women's leadership within state legislatures; and to elevate issues of special concern to women through research, educational programming and sharing of policy options.

The federal government is working feverishly on health care reform, as are many of the states. Access to care for the millions of uninsured will certainly be one of the outcomes of reforming our health care delivery system. This means preventive care will become a bigger part of health care.

Education on how to lead a healthy lifestyle is certainly a part of preventive care. It is the only way to reach adolescents in an attempt to prevent adolescent HIV infection.

AIDS is the sixth leading cause of death among young people 15-24. How do they become infected? The answer is obvious--primarily through unprotected sex. Education promoting both abstinence and the use of condoms is essential.

Many school systems mandate AIDS education. Some individual schools, particularly in urban areas, are making condoms available to students at school based clinics. It is particularly important that young women who are being given either birth control pills or Norplant be thoroughly counseled that they must also use condoms as a protection against HIV infection and other sexually transmitted diseases.

Studies and surveys have shown that although a large percentage of youths are sexually active, many with multiple partners, they do not use condoms all the time. Among teens who drink and use drugs the percentage is even smaller.

If we are to prevent HIV infection among adolescents, their families, schools, churches and community organizations must somehow reach them with adequate information and condom availability.

State Senator Paula Hollinger
Chairperson, Women's NETWORK
EXECUTIVE SUMMARY COMMENTS

The AIDS epidemic threatens to rob us of a whole generation of young people. Rates of reported AIDS cases are growing faster in young adults than in any other age group. Young, heterosexual women are disproportionately stricken. AIDS is no longer a disease only of major urban areas; small metropolitan, suburban and rural areas are experiencing increasing rates of diagnosed AIDS cases.

While it might be easier to pretend that AIDS is another legislator's problem or a problem in another state, the truth is that if any teenagers in your district have unplanned pregnancies, if any teens have sexually transmitted diseases, and if any teens from your area have unprotected intercourse with infected teens or adults from other areas, the potential for an HIV infection in your community exists.

As a former Maine state legislator and member of the Human Services Committee, I know that it is hard to make prevention a priority, particularly in tough budget years. I understand that immediate issues always loom large. I also know that many legislators are uncomfortable thinking about teenagers and sex, drugs and alcohol. I also know that we lack the rigorous evaluation to know exactly what will make young people delay sexual activity and practice safer sex. But we must try.

The current annual cost of treating a person with AIDS is $38,400, probably enough to pay for an undergraduate degree at your state university. Last year the Centers for Disease Control and Prevention estimated that the state and federal government spent $10.3 billion for treatment for a disease for which we currently have no cure. Another $15 billion was lost in potential taxes from people who died from AIDS in 1992.

The following pages contain information about components of programs which will give young people the information, motivation, skills and services needed to protect themselves from HIV infection. Policy recommendations are included that will allow citizens at the local level to design programs which are best for their children. The Center for Population Options stands ready to provide further information to legislators with information and technical assistance to local programs.

We can and we must assist young people to protect themselves from this deadly disease.

Margaret Pruitt Clark
Executive Director
The Center for Population Options

AUTHOR'S NOTE

This report could not have been written without the insight and editorial assistance of Margaret Pruitt Clark, Pamela Haughton-Denniston, Jennifer Hincks Reynolds, Jay H.S. Coburn and Kathleen Farrell nor without the research assistance of Janet Riessman, Claudia Page and Susan K. Flinn, all of whom are my colleagues at the Center for Population Options.
EXECUTIVE SUMMARY

While the actual number of adolescents with AIDS is low, young adults constitute almost 20 percent of the cases known by the Center for Disease Control and Prevention. Given the long incubation period for the disease, it is probable that these young adults were infected as adolescents. Every teenager is at potential risk for contracting HIV, the virus that causes AIDS, and must be armed with prevention-focused information, skills, materials and services.

One-half of all American adolescents are considered to be moderately to extremely at-risk of failing to make a successful transition to adulthood. Many of the behaviors that put them at risk for a variety of negative outcomes are the same ones that put them at risk for HIV infection. Some teens are at higher risk than others because of behavioral, socioeconomic or environmental factors. Those "teens in high risk situations" include runaway and homeless youth, detained or incarcerated teens, alcohol- and other drug-using youth and their sexual partners, out-of-school youth, adolescents in rural communities, gay youth, immigrant youth, and survivors of childhood sexual abuse, African-American and Hispanic youth and young women.

Challenges to adolescent HIV/AIDS prevention efforts include: the risk-taking and sense of personal invulnerability that is part of normal adolescence; teens' lack of refusal and negotiation skills; the difficulty in fostering behavior change; lack of evaluation research on prevention programs and on adolescent sexual behavior; limited school-based and non-school-based HIV/AIDS education; and adolescents' lack of access to health care, alcohol/drug treatment services and condoms.

A recent analysis of successful prevention programs has yielded 11 program components that should be part of effective HIV/AIDS program. The two most widely applicable are intensive, individualized attention and community-wide, multi-agency approaches. Six major points that prevention experts agree upon are that: 1) there is no single program component that by itself can alter the outcomes for all children at risk; 2) high-risk behaviors are interrelated and prevention programs should have holistic goals; 3) a package of services is required within each community; 4) interventions should be aimed at changing institutions; 5) early intervention is critical; and 6) one-shot programs have no effect.

In this report, three model HIV/AIDS prevention programs are highlighted that are providing comprehensive, intensive services to young people at high risk for HIV infection.

Fighting the spread of HIV in the adolescent population is possible. This report concludes with six policy recommendations: 1) create mechanisms for encouraging collaboration within communities and state agencies; 2) support comprehensive school health education and services; 3) support provision of HIV/AIDS education in non-school settings and to youth in high-risk situations; 4) support health promotion campaigns and the "social marketing" of condoms; 5) require and fund meaningful program evaluation; and 6) support the proper use of counseling and HIV antibody testing of adolescents.
INTRODUCTION

American Adolescents Are at Risk for Infection with HIV

The threat that the HIV/AIDS epidemic poses to today's adolescent population has major budgetary and policy implications for state legislators in every state in the nation.

American adolescents are at serious risk for infection with human immunodeficiency virus (HIV), the virus that causes acquired immunodeficiency syndrome (AIDS). While AIDS is not highly visible in the adolescent population--less than 1 percent of the national AIDS cases reported to the Centers for Disease Control and Prevention (CDC) are among teenagers--adolescents are among the fastest growing group of people with AIDS.1

As of December 1, 1992, 946 cases of AIDS among teenagers (ages 13-19) were reported to the CDC. However, 9,582 cases of AIDS were reported for those ages 20 to 24 and 38,713 cases for 25-29 year-olds. Given the average ten year period between infection with HIV and onset of AIDS-related symptoms, the majority of 20-29 year-olds with AIDS were infected during their teenage years. Close to twenty percent of all AIDS cases reported to the CDC are among 20-29 year-olds.2

There is no cure for HIV infection or AIDS, nor is one expected soon. The only way to halt or reduce further spread of the virus is to work diligently, creatively and resourcefully to provide the information, skills, services and materials that, if used correctly and consistently, will help adolescents protect themselves from becoming infected.

The majority of U.S. teenagers are engaging in sexual behaviors that increase their risk for HIV infection. According to the CDC's 1990 Youth Risk Behavior Study, 39.6 percent of ninth graders, 47.6 percent of tenth graders, 57.3 percent of eleventh graders and 71.9 percent of twelfth graders report ever having had intercourse. More than 19 percent of all high school students have had four or more sex partners.3

While latex condom use among teens is on the rise, almost half of adolescents engaging in sexual intercourse do not use them.4

It only takes one infected individual in any school, town or community to start a chain of infection among healthy adolescents. Young people are mobile; they visit neighboring cities and

1 Centers for Disease Control and Prevention, HIV/AIDS Surveillance (October 1992).
towns. They experiment; they try alcohol and other drugs. They have unprotected sexual intercourse. They think that a "long-term" relationship is six months long. One infected adolescent who has unprotected sexual intercourse or shares a needle with another teen can set in motion a series of infections.

Communities that are not affected by HIV today will most assuredly be affected in the future; solid prevention programming now will help keep teens in those communities safe and therefore HIV/AIDS prevention education must be made available to all teens.

Even if adolescent AIDS cases are not yet reported in a given town or county, teen pregnancy rates and the rates of sexually transmitted diseases (STDs) give a good indication of the future of the HIV epidemic. In towns and states with high teen pregnancy and STD rates, young people are already engaging in the unprotected intercourse that can effectively transmit HIV.

HIV infection is invisible; it is possible that symptoms will not occur for a decade or more. During those healthy years, however, those infected can still infect others. Most teens who are infected with HIV, like most adults, do not know that they have the virus. Just because there are no reported AIDS cases in a given community does not mean that there are no persons infected with HIV.

All teens are at risk for infection with HIV if they engage in sexual intercourse or share needles with an infected person, but at this stage of the epidemic, teens in certain situations are more likely to be exposed to HIV. HIV/AIDS prevention messages, programs and services targeted to African-American, Hispanic, gay males, runaway and homeless youth and teens who use alcohol and other drugs are necessary. These are the teens who have experienced the worst of the epidemic and they live in every state in the U.S.

It is not just those youth, however, who need HIV/AIDS prevention education and services. Young women between the ages of 13 and 24 are experiencing the most rapid increase in the rate of AIDS diagnosis. The rate of reported AIDS cases is growing faster in small metropolitan, suburban and rural areas than in big cities. Survivors of childhood sexual abuse, who are in every state, seem to be at greater risk for engaging in risky behaviors that lead to HIV infection than other youth. Thus, teens in state are at risk.

Taking appropriate measures to deliver life-saving information and skills to all adolescents will save lives and dollars in the future.

The Cost of Not Addressing Adolescent Risk for HIV Infection

The Centers for Disease Control and Prevention estimates the cost of treating all people with HIV infection and AIDS in 1992 at $10.3 billion and at $15.2 billion in 1995. Currently, the yearly costs of treating a person with AIDS is $38,400; the cost of treating a person with HIV infection (someone who is sick but does not have an AIDS diagnosis) is $10,000.

6 Centers for Disease Control and Prevention, Business Responds to AIDS Manager's Kit (December, 1992), p. 4.
8 National AIDS Clearinghouse Hotline, information provided to author, February 9, 1993.
HIV infection and AIDS, because they largely affect young people, will soon surpass all other diseases in creating a loss of human economic potential. The approximately 51,000 deaths in 1992 of people with AIDS translate to 1.55 million working years those people might have put in before age 65. At an average income of $30,000 per year, the decrease in future income will be $46 billion due to deaths in 1992 alone. The combined Federal and state tax revenue loss is in the range of $15 to $20 billion dollars.  

9 William A. Mundell and Jack Friedman, "AIDS True Costs Should Determine Funding" (Bala Cynwyd, PA: WEFA Group, 1992).
CHALLENGES TO ADOLESCENT HIV/AIDS PREVENTION EFFORTS

Adolescent HIV/AIDS prevention efforts have been stymied by a variety of barriers, including lack of adequate evaluation data, community climate, adolescent developmental issues and lack of comprehensive programs addressing information, skill-development and access to medical services.

Adolescent Behavior

Risk-Taking Is a Part of Normal Adolescent Development

Normal adolescent emotional and cognitive development is a contributing factor to adolescent HIV infection. Teens are risk-takers, not because they want to hurt themselves (or their families) but because one of the "tasks" they must accomplish on their way to adulthood is emancipation from their families. They must leave their childhoods behind and emerge, after some years of exploration and growth, as young adults. Pushing limits and testing boundaries are ways to accomplish this difficult task.

Risk-taking is instrumental in: gaining peer acceptance and respect (going along with group norms and activities); establishing autonomy from parents; affirming maturity (engaging in behaviors that are sanctioned for adults); and creating distance from conventional authority. Young Americans have been taking risks for generations. What has changed are the stakes. Now, with the threat of HIV looming over America's youth, engaging in risky sexual or drug-taking behavior can lead to early death.

Adolescents' cognitive development may hamper their ability to act wisely while satisfying their need for independence. Generally, teens in early adolescence (12-14) possess thought patterns that are still relatively concrete; they have difficulty projecting themselves into the future. It is difficult for young people at this developmental stage to modify their behavior based on a theoretical threat in the future.

Young people in middle to late adolescence are cloaked in what one expert humorously terms "the Armor of Middle Adolescence." The armor consists of "the Helmet of Omniscience which makes them all-knowing, the Breast Plate of Omnipotence which makes them all-powerful and the Shield of Invincibility which gives them the ability to defend against and defeat every foe." Those "armaments" allow adolescents to participate in all sorts of risky activities, including athletics and other activities sanctioned by society, in the firm belief that they will not be harmed.

10 Robert Johnson, Testimony to the U.S. House of Representatives Select Committee on Children, Youth and Families, May 5, 1992. Dr. Johnson is the Director of the Division of Adolescent Medicine at the New Jersey Medical School in Newark, NJ and Chair of the Board of the Center for Population Options.
The strong sense of personal invulnerability allows many of today's teens to cling to myths and naive assumptions about the possible risks of unprotected sexual activity. For example, many adolescents believe that healthy or clean-looking people cannot be infected with HIV or that someone who professes to love them would never lie about infection or past risky behavior.

Relatively few adolescents have AIDS and the many that are infected with HIV are invisible from their peers, feeding adolescent denial of the risk of infection. Adolescents are notorious for their perceptions of invulnerability; breaking through that wall and making the HIV threat real to them is a very challenging task.

In addition to a sense of personal risk, however, teens need a feeling of self-efficacy, an ability to make necessary changes. For many teens, this feeling of personal power is weak. For adolescent girls, in particular, it is worth noting that recent research indicates that it is during adolescence that girls lose the childhood assertiveness skills and self-knowledge that would stand them in good stead as they face the challenges of growing up healthy in today's world.\textsuperscript{11} Traditional sex roles that foster female passivity linger, making it difficult for many young women to feel empowered enough to protect themselves, even when they have knowledge about safer sexual practices.

**Lack of Negotiation and Refusal Skills**

The entire complex of problems associated with adolescent sexual behavior (including unplanned pregnancy and the sexually transmitted disease and HIV epidemics) have roots in teens' lack of skills in the whole area of sexual behavior negotiation. Even adult Americans often have difficulty communicating with their partners about sexuality. Adolescents have just as much difficulty, if not more, due to their inexperience.

Negative peer pressure has long been cited as a factor in young people choosing to engage in unhealthy or risky behaviors. Skill-building in the area of refusal skills would help adolescents stand firm against peer pressure to experiment with sexual activity or alcohol and other drugs.

Prevention programs that expect adolescents to "just say no," to ask a partner to use a condom or to resist peer pressure to use alcohol and other drugs without providing the opportunity to practice negotiation and refusal skills will not be successful with the majority of teens.

**Behavior Change Is Complex and Difficult to Achieve**

Designing HIV/AIDS prevention programs that work is a great challenge. Many of the behaviors that need to be changed are highly entrenched and very difficult to alter. The emotional, social and physical needs that are met through sexual or drug-taking activity are exceedingly complex, rooted in basic needs for love, security and pleasure, among others.

When a young person is asked to end a sexual relationship or to introduce the idea of condoms to a partner, that person might be risking the loss of a very important relationship that provides him or her with love, companionship, intimacy, security and status. For a youth living on the street, exchanging sex for money, food, shelter or drugs, the loss of basic human needs is risked.

When a young person using injection drugs is asked to stop using drugs, he or she risks losing the desired effects of the drug while experiencing withdrawal symptoms. Asked to stop sharing needles, a youth risks the loss of peer acceptance and the opportunity to get high. Asked

to clean needles with bleach and water, a drug-using adolescent risks loss of ease and speed of drug injection.

HIV/AIDS prevention programs ask teens to weigh the immediate loss of very important feelings, relationships, identity, experiences and tangible goods with the possible loss of life in ten or more years. Is it any wonder that it is difficult to change adolescent risk-taking behavior?

Behavior change research is clear on two counts. The first is that information alone is insufficient to change behavior. Early HIV/AIDS prevention efforts focused on telling adolescents (and adults) the facts: how HIV is transmitted, how one can protect oneself from infection, what AIDS is and so on. Just learning about a deadly disease, however, does not provide motivation to change, for reasons outlined above. Thus, HIV prevention programs that are designed solely to provide information to young people will not be effective. Preventive efforts that consist of school information-only curricula and items such as informational videos, brochures and posters may provide important health-related information to teens but it is unrealistic to expect these measures alone to engender much behavior change.12

The second lesson from behavior change research is that a comprehensive model that combines information-giving with skill-building and access to services is much more likely to bring about the desired change. Young people need, in addition to information and awareness, a sense that HIV is a threat to them (termed “personalizing risk”), the skills (i.e. negotiation, assertiveness and refusal) and tools (i.e. condoms), and the opportunity to practice. The federal Office of Technology Assessment (OTA) reports that “preventive efforts that change environments, provide some form of concrete aid or improve competencies are more effective primary prevention strategies than are strictly didactic education-based interventions.”13

Evaluation, Research and Data

Lack of Evaluation Research

Evaluation of prevention programs in general is sorely lacking. Although work to prevent a variety of behaviors has been conducted by thousands of agencies over the last 20 years, little long-term evaluation data have been collected, analyzed or disseminated. Attempting to measure whether behavior change is caused by a particular program intervention is very difficult, time-consuming and expensive.14 Most substance abuse, pregnancy, school drop-out and delinquency prevention programs have not been adequately evaluated; even those cited as models often lack long-term outcome research that would prove their long-term effectiveness.

Some of the obstacles that impede evaluation of the effectiveness of HIV/AIDS prevention programs include limited funds or time, lack of technical expertise and methodological difficulties such as tracking transient populations and distinguishing a program’s effects from other environmental factors. Due to the difficulty in mounting rigorous scientific evaluations of behavior change, most HIV/AIDS prevention programs have undertaken "process" evaluations

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13 Ibid.
alone, collecting data about the implementation of the program that fall short of providing hard evidence that these programs work in the long run to prevent HIV infection.\textsuperscript{15}

Useful evaluations that measure outcomes (or impact) of programs are not quickly done. Programs need sufficient time to refine goals and strategies based on experience. Program participants should be followed for a reasonable length of time.

\textbf{Lack of Data on Adolescent Sexual Behavior}

Since HIV is a virus that is transmitted sexually, the first step in designing adequate prevention programs for adolescents would be to describe accurately sexual behavior. To be useful, a description must include specific sexual activities teens engage in, with what sexes, at what ages and how often. Unfortunately, due to the extreme discomfort such research questions engender and the misperception that asking teens such questions will cause them to experiment, there have been no studies providing data to answer any of the important questions related to adolescent sexual behavior in recent years.

Studies of the scale necessary are very expensive and require government funding. Two studies, one focusing on teens, that would have provided data useful for designing programs to combat HIV, other sexually transmitted diseases and unplanned pregnancy were cancelled by the Bush Administration in 1991.

\textbf{Community Climate and Educational Programs}

\textbf{The Community Climate and Its Effects on Prevention}

Few would debate that the issues raised by the AIDS epidemic—sexuality, drug use, death—are difficult ones for most adult Americans to talk about openly or calmly. Adding the adolescent element stirs up even more emotion: most adults are profoundly uncomfortable with adolescent sexual activity, particularly homosexual activity, and deeply concerned with adolescents' use of alcohol and other drugs.

While communities vary in their levels of discomfort, it is fair to note that the prevailing climate in the U.S. since the beginning of the epidemic has hampered effective HIV/AIDS prevention efforts in a variety of ways. Research on adolescent sexual behavior has been cancelled, school HIV/AIDS education has been watered down or not implemented at all and access to condoms has not been fostered.

\textbf{Limited School-Based HIV/AIDS Education}

The Sex Information and Education Council of the U.S. (SIECUS) analyzed state HIV/AIDS programs and reported weaknesses in both the content of curricula/guidelines and in program design.

All states have responded to the HIV/AIDS epidemic in part by requiring or recommending HIV/AIDS education in the schools, the logical place to reach most young people. Over two-thirds (38 states) require HIV/AIDS education through state law or education department policy. Almost all states place HIV/AIDS education within the logical framework of

the health education curriculum and all states provide the rarely-used parental option to excuse their children from HIV/AIDS instruction.16 Grave shortcomings, however, in curricula/guidelines and program design have been identified. Many state programs fail to provide young people with all the information they need to avoid or reduce their risk of becoming infected with HIV. Despite the fact that young people need a combination of 1) information about the virus and its spread, 2) a belief that they are at risk, and 3) the skills to take appropriate preventive measures, only three states17 have curricula/guidelines that adequately address all three learning domains (cognitive, affective and skill).

Weaknesses in curricula and guidelines might include:

- a lack of instruction about sexual responsibility and decision making;
- failure to discuss human sexuality in a positive framework;
- material often not presented in a developmentally age-appropriate manner;
- inadequate instruction on condom use;
- over-emphasis on abstinence that often results in omission of discussions about safer sexual practices;
- absence of discussion of issues about sexual orientation;
- inadequate instruction about compassion for people with HIV/AIDS.18

The design of many state programs may be hampered by:

- inadequate teacher training;
- failure to monitor program effectiveness;
- limited implementation by local school districts;
- failure to regularly update curricula and guidelines, despite the fairly rapid increase in the knowledge-base.19

In addition, too many school-based HIV/AIDS education efforts do not start early enough, in the primary grades, when a foundation for healthy behaviors can be laid. There is also a lack of interaction between the drug abuse prevention and HIV prevention efforts and the two clearly should be linked.

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17 Massachusetts, New Jersey and South Carolina
18 Britton, De Mauro and Gambrell, p. 4.
19 Ibid.
Limited HIV Education in Non-School Settings

Community-based organizations, traditional youth-serving agencies, church groups and youth recreation programs all have the potential to reach young people in non-school settings with HIV/AIDS prevention programs. While some of those organizations have taken important steps in providing teens with HIV/AIDS prevention programs, many others have left the task to schools or other organizations. For youth in high-risk situations, particularly those who are out-of-school, prevention programs in non-school settings might be the only programs with which they have contact. If those programs do not seize the opportunity to provide HIV/AIDS prevention education, those young people are left without the information, skills and access to services that they need to protect themselves from HIV infection.

Access to Services and Prevention Efforts

Lack of Access to Health Care

One out of seven adolescents, 4.6 million overall, lacks insurance coverage, including one out of three poor teens who is not covered by Medicaid. Even those adolescents with health insurance may be ineligible for mental health and substance abuse services. Without health care coverage, young people are without the benefit of a relationship with a regular health care provider who might be able to help assess risk for HIV and other diseases.

In addition to the uninsured, some adolescents are more likely to be without quality health care than others, including:

- adolescents who are not aware of the existence of services;
- adolescents whose only access is to urban public health clinics that appear unapproachable;
- adolescents in actual or potential conflict with their parents about the receipt of health services for which they must have parental consent;
- homeless adolescents;
- adolescents who may live in parts of rural America with few or no providers of health care or have no transportation to the few that exist;
- African-American, Hispanic, American Indian and Alaska Native adolescents because half of them live in families with incomes below 150 percent of the federal poverty level;
- adolescents incarcerated in juvenile justice facilities.

Other young people also may lack adequate health care. Non-English speaking teens may not have access to health care providers who speak their language and may misunderstand, or be

21 Ibid., p. 111.
22 Ibid., pp. 26-27.
misunderstood. Gay and lesbian adolescents may not reveal their sexuality to health care workers and thus miss an opportunity for honest interaction.

Intangible barriers exist as well: in too many cases those health care providers who do interact with adolescents have received no specialized training in adolescent medicine and therefore are unlikely to be properly equipped to deal with the emotional/social needs and concerns of young people. It is not uncommon for a practitioner to approach adolescent patients on the basis of stereotypes, for example, treating a 16-year-old like a 12-year-old and thus failing to ask questions about sexual activity. Providers may have difficulty overcoming their own denial and acknowledging that teens are experimenting with sex, alcohol and other drugs.

Lack of Access to Condoms

For sexually active teens, proper use of latex condoms is the recommended prevention method. Having access to condoms is the first step; using them consistently and correctly is the second.

Condoms may appear to be widely available, but a number of factors inhibit young people's ability to acquire and effectively use them. Surveys have found that lack of availability is one of the most frequently cited reasons sexually active adolescents fail to use condoms. Furthermore, adolescents' desire for confidentiality often overshadows their concerns for health. While fear that others will learn they are sexually active does not keep teens from having intercourse, it does apparently inhibit them from purchasing condoms. Other factors, many of which are associated with low self-esteem, perceived by teens as barriers to regular condom use include: peer or partner pressure; fear of loss of relationship; fear of decreased sexual pleasure; cultural expectations for gender-related behavior and roles; denial of sexual activity; use of drugs and alcohol which impair judgment, contributing to risky behavior and failure to use condoms properly or at all; anxiety about being seen by parents, friends or neighbors when purchasing condoms or by harassment by store clerks; and cost.

A 1988 survey by members of the Center for Population Options Teen Council examined the accessibility of contraceptives, including condoms, in drugstores and convenience stores in Washington, D.C. and found that: one-third of the stores kept condoms behind the counter, forcing teens to ask for them; only 13 percent of the stores had signs that clearly marked where contraceptives were shelved; adolescent girls asking for assistance encountered resistance or condemnation from store clerks 40 percent of the time. For adolescents these obstacles represent significant barriers to condom access. Evidence from other parts of the country suggest that Washington, D.C. is not unique.

Even in areas where health departments or family planning clinics provide condoms free of charge and without appointments, school or work obligations may combine with clinic schedules to make it difficult or impossible for adolescents to take advantage of these services. Rural youth, in particular, have concerns about privacy. Being seen by someone known to the teen or the teens' parents is more likely in a drug store or clinic located in a small town or rural community. Lack of transportation to clinic sites is a significant barrier in many rural areas.

23 Robert Johnson, testimony.
Lack of Access to Drug and Alcohol Treatment

Abstinence from sexual activity or proper use of latex condoms are not the only ways to reduce risk of HIV infection. HIV can be transmitted during the sharing of needles used in injection drug use and other needle-sharing activities such as tattooing, piercing or blood-brother rituals. In roughly one out of eight diagnosed cases of AIDS among teens, injection drug use has been implicated as a risk factor. Among females ages 13-19 who have been diagnosed with AIDS, 28 percent are related to injection drug use.\textsuperscript{25}

For those adolescents who use alcohol or other drugs, barriers to treatment include reticence in seeking school-based services for fear of suspension or expulsion; lack of valid assessment tools to identify which adolescents need treatment; and a dire shortage of alcohol and other drug abuse treatment services for teens.\textsuperscript{26}

Concerns about the current substance abuse treatment system for adolescents include the lack of objective, standardized criteria for admission; potentially inadequate training of personnel; the absence of methodologically rigorous evaluations of treatments; and lack of access to early intervention.\textsuperscript{27}

Youth in High-Risk Situations

One-half of all American adolescents are vulnerable to multiple high-risk behaviors and school failure. The Carnegie Council on Adolescent Development estimates that seven million young people--one in four adolescents--are extremely vulnerable and that an additional seven million are at moderate risk.\textsuperscript{28}

While any adolescent is at risk for contracting HIV, there are some American teens who are at higher risk than others because of behavioral, socioeconomic or environmental factors. Those teens are referred to as "youth in high-risk situations."

Behavioral risk factors include such behaviors as having unprotected sexual intercourse with possibly infected individuals, engaging in "survival sex" (sex in exchange for food, money, drugs or shelter), running away from home or committing a crime that leads to incarceration. Socioeconomic and environmental factors include low socioeconomic status (which disproportionately affects communities of color), sexual abuse, homelessness, out-of-school status (having dropped out), alcohol/drug-addicted or abusive parents, and learning disabilities/emotional disturbance.\textsuperscript{29} There are thousands of young people in high-risk situations in every state in this country who would benefit from targeted HIV/AIDS prevention programs and services.

\textsuperscript{26} U.S. Congress, House, Select Committee on Children, Youth and Families, A Decade of Denial: Teens and AIDS in America 102nd Congress, 2d sess., May, 1992, p. 153.
\textsuperscript{27} U.S. Congress, Office of Technology Assessment, Adolescent Health--Volume II, p. 100.
High Risk Youth Populations

The following pages will highlight the problems and challenges of youth in a variety of high-risk situations. Individual adolescents, of course, may be affected by more than one of these situations. For example, a homeless teen might be a survivor of childhood sexual abuse, an African-American boy might be gay, a rural youth might be an alcoholic or a young woman might be a recent immigrant.

Runaway/Homeless Youth

A startling number of American adolescents live on the streets or sporadically in shelters. The National Network of Runaway and Youth Services estimates that between one and 1.3 million teens run away from home every year due to conflict, violence and abuse. A growing number of teens are homeless because their entire families are homeless.

Homelessness is one of the most risky situations for adolescents. Those homeless teens that run away from or are thrown out of their homes generally come from deeply troubled, severely abusive families with histories of emotional, physical or sexual abuse and substance abuse. Many teens are thrown out of their homes after revealing a gay, lesbian or bisexual orientation.

The effects of family dysfunction and rejection are profound. Runaway and homeless youth are plagued by low self-esteem and may suffer from depression, suicidal behavior and mistrust of adults. Their difficult backgrounds can lead these young people into pursuing high-risk and self-destructive behaviors.

Exchanging sexual activity for money, food, shelter or drugs is termed "survival sex" and is common among both male and female teens living on the streets. Selling their bodies often is the only way they have of finding food to eat or a place to sleep or for supporting a drug addiction. Reports from youth outreach workers indicate that youth are often offered more money for engaging in unprotected intercourse. Many teens opt to meet their more immediate needs rather than act to reduce longer term risks.

In a study conducted by a shelter serving runaway and homeless youth, 142 youth--more than 5 percent--were infected with HIV.

For homeless adolescents, for whom daily survival is of paramount concern, HIV/AIDS is simply not viewed with the alarm prevention workers would wish. Adolescents who struggle daily for food and shelter minimize the threat of a disease that might affect them in 10 years.

Any effective HIV/AIDS prevention work with this population must address basic human needs and incorporate strategies for building trust.

Although the picture painted by the media and by AIDS advocates of homeless youth is grim, their situation is not hopeless. The stereotype that homeless and runaway youth are beyond help inhibits many prevention programs and service providers from serving these youth. In fact, not all homeless and runaway youth are engaged in survival sex or drug abuse. Twenty-five

30 National Network of Runaway and Youth Services, To Whom Do They Belong?: Runaway, Homeless and Other Youth in High-Risk Situations in the '90s. (Washington: D.C, National Network for Runaway and Youth Services, 1991)
32 U.S. Congress, House, Select Committee on Children Youth and Families, Decade of Denial, p.124.
percent of these youth are sexually abstinent, female runaways typically have been involved sexually with only one partner in the last three months and males typically have two to four partners in the same time. According to the Government Accounting Office (GAO), approximately four out of five homeless adolescents do not appear to have an alcohol or other drug problem.

Incarcerated Youth

In 1989, a total of 1,228,000 youth were detained in 1,100 facilities. Racial minorities are disproportionately represented in detention centers, accounting for approximately 60 percent of presently detained youth. The young people living in juvenile detention facilities or adult prisons are at risk for HIV infection for both personal and environmental reasons.

Research suggests that incarcerated youth lack a future orientation, have poor self-image and perceive little or no value in modifying risk behaviors. They generally do not take good physical care of themselves, tend to underestimate their risk for HIV infection, have lower personal efficacy to prevent HIV infection and believe that their peers do not engage in safer sexual practices.

Environmental constraints that present barriers to effective HIV/AIDS prevention interventions include: detention facility bans on discussion of sexuality or drugs; reluctance of officials to allow condoms to be made available to youth in detention; limited financial and personnel resources; and the transient nature of the population.

Alcohol and Other Drug-Using Youth and Their Sexual Partners

The most obvious HIV risk factor associated with drug use is the sharing of needles or "works" (syringes, cocaine 'cookers' and other paraphernalia) during injection drug use. Infected blood can be left on or in the instruments and then injected directly into another person's bloodstream.

Sharing needles and works is a common ritual among injection drug users and a very effective vector of HIV transmission. Although most drug use among teens does not involve injection, 10 percent of those in drug abuse treatment programs who reported intravenous drug use during the previous year were age 21 or younger.

33 U.S. Congress, House, Select Committee on Children, Youth and Families, Decade of Denial, p. 124.
36 Ibid., p. 59.
38 Morris, Baker and Huscroft, p. 59.
In roughly one in eight diagnosed AIDS cases among teens, injection drug use has been implicated as a risk factor. 40

In addition to the dangers associated with injection of drugs such as heroin and cocaine, some American teens, mostly boys, share needles during illegal steroid injection. Searching for the perfect body or the bulk needed to succeed on the playing field, adolescents are injecting themselves with steroids. Of the high school senior respondents in a large National Institute of Drug Abuse (NIDA) survey, 2.9 percent reported the use of steroids (which are injected by 99 percent of users). 41

The sexual partners of injection drug users are at high risk for HIV infection, whether or not they themselves use injection drugs.

More common than injection drug use by adolescents is the use of non-injection drugs and alcohol that can lower inhibition and adversely impair judgment, increasing the likelihood that a young person will engage in risky sexual behavior. 42 The best-laid HIV prevention plans can go awry when a teen is under the influence of a mind-altering substance.

Out-of-School Youth

Adolescents who have dropped out of high school, or who are in and out of school, face a myriad of problems in a changed economy that no longer provides well-paying or secure jobs for those with minimal skills. Out-of-school youth often suffer from psychological problems such as depression, anxiety, low self-esteem and even suicidal thoughts. 43 As a result of these difficulties and in response to the general disaffection they feel, out-of-school youth frequently engage in high-risk sexual activity and alcohol and other drug use.

These young people are very socially isolated; often, their peers in similar situations are the only real connection they have to others. There is an absence of adult guidance and support and often an extreme lack of access to medical and social services.

Out-of-school youth quite obviously will not benefit from school-based HIV/AIDS prevention programs; other ways of reaching this population must be employed. Community-based organizations, youth-serving agencies, recreation centers and the like have been successful in reaching teens who are not in school.

Rural Youth

HIV and AIDS are no longer confined to the largest cities in the U.S. The rate of reported AIDS cases is growing faster in small metropolitan, suburban and rural areas than in big cities.44

The federal government's HIV/AIDS prevention dollars have primarily targeted cities with high-incidence rates. Continued lack of funds and programming for rural prevention efforts will only increase the numbers of infected adolescents and adults in the years to come.


Participants' descriptions of rural youths' lives revealed a population that is isolated, bored and prone to alcohol and drug use. Many teens live miles from friends or gathering places. Youth boredom was widely reported: in most rural communities there are no socially-sanctioned spaces to "hang out" and few, if any, activities geared toward young people. Sexual activity and use of alcohol and other drugs is common, although often denied by the adult community.

Symposium participants reported the following challenges they experienced in providing HIV/AIDS prevention programs in their communities:

* conservative attitudes towards sexuality;
* community denial of adolescent sexual activity, alcohol and other drug use and subsequent HIV risk;
* lack of confidentiality (small-town gossip and its effects on adolescent condom purchase, for example);
* isolation of youth/distance between homes;
* personal risk to staff (very real danger of taking on a controversial issue and becoming a target for the religious right);
* limited resources (lack of funds, staff and programs).45

Restrictions on the content of HIV/AIDS education are common in rural communities. In a field test of HIV/AIDS curricula in rural schools, curriculum materials were selected on the basis of compatibility with traditional, conservative community values.46

Immigrant Youth

Adolescents who are recent immigrants to this country face struggles with the education, health care and social service system similar to those faced by their families, and by generations of

44 Centers for Disease Control and Prevention, Business Responds to AIDS Manager's Kit.
immigrants before them. Language barriers, economic stresses, cultural rifts and other problems provide great challenges in providing adequate HIV/AIDS prevention to this population.

When immigrant teens arrive in the U.S., they face pressures to adopt the behavioral practices of those born in the United States. Research indicates that adolescents from other countries are more likely than their U.S.-born peers to believe that persons their age engage in HIV-related risk behaviors. Students who immigrated to this country in the year prior to the survey were most likely to believe that no one their age uses condoms and that everyone their age injects illegal drugs. It seems reasonable, then, that immigrant teens might feel disproportionate pressure to adopt risky behavior in order to fit in with their new peers.

Survivors of Childhood Sexual Abuse

The number of Americans who have been sexually abused is enormous. Estimates vary and are probably low due to underreporting but current statistics indicate that approximately 27 percent of women and 16 percent of men experienced some form of childhood sexual abuse. The abuse occurs most often in the home and by someone the young person knows and trusts.

Data suggest that childhood sexual abuse survivors are at particular risk of HIV infection due to the long-term effects of the abuse on emotional development and self-esteem. In a 1990 study, 34 HIV positive adolescents ages 12-20 were interviewed; 41 percent reported histories of childhood sexual abuse.

Common effects of sexual abuse that relate directly to survivors' abilities to protect themselves from HIV have been identified:

* Teens need some sense of personal power and hope but survivors of abuse often feel tremendous guilt and depression.

* A sense of self worth is critical for adolescents to keep themselves safe but childhood sexual abuse survivors often have low self-esteem, a sense of shame and a belief that they are "damaged goods."

* Some ability to set limits and boundaries is helpful for teens in remaining abstinent, consistently using condoms or not sharing needles, but survivors often feel out of control and frequently "dissociate" (essentially, tune out) under stress.

* Survivors have great difficulty with trust, intimacy and communication, yet effective HIV risk reduction techniques involve all three.

49 Dekker et al., "The Incidence of Sexual Abuse in HIV Infected Adolescents and Young Adults."
Clear judgment is required to continue to practice HIV prevention, yet many sexual abuse survivors turn to alcohol and other drugs to numb their pain.

Many of the personal strengths teens need to protect themselves from HIV infection are exactly those which a history of childhood sexual abuse impairs. Given the prevalence of childhood sexual abuse in this country, the impact of this abuse cannot be ignored by any HIV/AIDS prevention program that hopes to modify teens' behavior.

Lesbian, Gay and Bisexual Youth

Lesbian, gay and bisexual youth face serious challenges to growing up physically and mentally healthy in a dominant anti-homosexual culture. Often, these youth face an increased risk of medical and psychosocial problems, caused not by their sexual orientation, but by society's extremely negative reaction to it. Gay, lesbian and bisexual teens face rejection, isolation, verbal harassment and physical violence at home, at school and in religious institutions. Responding to these pressures, many of these youth engage in an array of risky and self-destructive behaviors, many of which can lead to HIV infection.

Sixty percent of young adult cases of AIDS (ages 13-24) are among males who have had sex with males. A San Francisco study of young gay men indicated that gay males between the ages of 17 and 19 were more likely to engage in unprotected anal intercourse than men between the ages of 20 and 25. In the sample, just over 14 percent of young men between 17 and 22 were HIV positive compared to 10.4 percent of young men between 23 and 25 year old.

There is a strong correlation between homosexual orientation and homelessness noted in several studies. For example, in a 1986 survey of street youth in Seattle, 40 percent of the youth identified themselves as gay, lesbian or bisexual. One in four gay or bisexual males is forced out of the home prematurely due to family conflict surrounding sexual orientation and up to half resort to prostitution in order to support themselves, thereby dramatically increasing their risk of HIV infection.

Some particular challenges to providing HIV/AIDS prevention education to lesbian, gay and bisexual youth include:

- widespread community denial of adolescent homosexuality;
- most gay, lesbian or bisexual youth do not identify themselves to parents, teachers or program leaders and most HIV/AIDS education programs assume that all the participants are heterosexual;
- young gay men have the erroneous perception that HIV is a disease only of older men and consequently engage in unprotected anal intercourse more frequently than older men.

52 AIDS Office, Bureau of Epidemiology and Disease Control, San Francisco City Clinic Special Programs for Youth and San Francisco Department of Welfare, The Young Men's Survey: Principal Findings and Results (San Francisco, CA: June, 1991).
53 Orion Center, Survey of Street Youth (Seattle, WA: Orion Center, 1986).
* young lesbians might believe that lesbians are "safe" because of widespread reporting in the 1980s that lesbians were the "lowest risk category." Thinking of risk categories is not useful; thinking of risky behaviors is. Lesbians sometimes have intercourse with men and they are not immune from injection drug abuse.

Some adolescents who engage in same-sex sexual behavior but do not identify as gay, lesbian or bisexual also need HIV/AIDS prevention interventions, yet they are unlikely to respond to messages aimed toward gay- or lesbian-identified youth. It is a particular challenge to reach these youth.

Young Women

Among teenagers, the HIV infection rate for girls is consistently higher than the rate for boys. A greater percentage of adolescents (13-19) than adults with AIDS are female (29 percent versus 12 percent) and were infected through heterosexual contact.

The best HIV/AIDS interventions for young women is probably somewhat different from those for young men. Preventing the sexual transmission of HIV for heterosexual girls and women involves communication with potential or current male sexual partners. A commitment to abstinence, if not shared by her partner, can be difficult to keep, particularly if the young woman's boyfriend is pressuring her. If she chooses to have sexual intercourse and wants to protect herself, the latex condom is her only realistic choice and its use requires male cooperation. (The newly-developed "female condom" is more expensive than the male condom, requires vaginal insertion and is not yet widely available.)

Adolescent girls, more than teenage boys, fall victim to a cultural belief that they should not plan for sex. Young women need assertiveness skills, self-esteem, a belief that they can control what happens to them and peer support to effectively negotiate abstinence or safer sex with male partners. Both young men and women need practice in using those skills and access to condoms.

Adolescent pregnancy data indicate that when the age of the father is known, 70 percent of births to teen mothers were fathered by men in their twenties, thirties, forties or fifties. The age disparity might add to a young woman's difficulty in negotiating condom use while at the same time increases the likelihood that the male has had multiple partners.

Contraception access and education present particular challenges with the female population. Young men only have one option: the condom. Young women have several more, the most popular of which, the pill, provides no protection against HIV transmission. Thus, health care workers have not only to convince young women to use birth control, but also to convince them to use condoms in addition to other forms of contraception.

Not all adolescent female sexual activity is consensual; in addition to childhood sexual abuse, rape is a danger for young women. Data indicate that 50 percent of all rapes are committed

Skills and services that would help reduce the incidence of childhood sexual abuse and rape can also be understood as a component of HIV/AIDS prevention.

**African-American, Hispanic and Other Youth of Color**

African-American and Hispanic adolescents are overrepresented in the adolescent AIDS population and there is growing concern that Native American and Asian American youth will soon experience a surge in HIV infection. Seventy-four percent of young women (13-24) diagnosed with AIDS are African-American or Hispanic. African-American applicants to military service between 1985 and 1989 were five times as likely to be infected with HIV than were white applicants.

Many of the challenges to HIV/AIDS prevention interventions for adolescents of color are rooted in issues that effect both young and old in their communities, principally poverty and discrimination.

A disproportionate number of youth of color live in poverty and grapple with all the social problems that come with lack of money, status and access to goods and services, including primary health care. In many communities suffering the stress of poverty and lack of opportunities, drug addiction has taken strong hold and a norm toward early sexual activity and parenting is in force. Introducing HIV/AIDS prevention interventions in these already-troubled communities is challenging.

The challenge is made even greater by community belief that AIDS is a gay, white male disease, denial of same-sex sexual activity, discomfort with issues of sexuality and distrust of the government.

For some time, rumors have circulated in the African-American community that the government is responsible for the HIV epidemic in that community. Suspicion exists among some members of the African-American community about the government's role in prevention and treatment of the disease. The history of the U.S. Public Health Service's involvement in the infamous Tuskegee Syphilis Study feeds that distrust. In that 40-year study, poor black men were deliberately left untreated for syphilis so that doctors could observe the long-term effects of the debilitating disease. The men had no knowledge of their infection. Some members of the African-American community have been understandably suspicious of HIV/AIDS prevention efforts that have relied on similar tactics used to recruit men to the Tuskegee Study.

In the early days of the AIDS epidemic, the U.S. government listed Haitians as a "risk group" for AIDS. The legacy of that labeling lingers, impeding prevention programming for

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59 National Victims Center and Crime Victims Research and Treatment Center, *Rape in America: A Report to the Nation* (Arlington, VA: National Victims Center and Crime Victims Research and Treatment Center, April 1992). 29.3 percent of sexual assault victims were under 11 years of age and 32.3 percent were between 11 and 17 years of age.


Caribbeans residing in the U.S.\textsuperscript{63} Lastly, the oft-heard assertion that "AIDS came from Africa" angers many African-Americans who hear that claim as another way to blame the victim.

SUCCESSFUL HIV/AIDS PREVENTION PROGRAMS

Components of Successful Programs

Noted prevention expert Joy Dryfoos analyzed 100 different programs that appear to have potential for changing behavioral outcomes for adolescents. The four areas of prevention that she studied were: teen pregnancy, substance abuse, school failure and delinquency. Although HIV/AIDS initiatives were not among those she examined, the lessons learned from her research about behavior change are applicable to that field as well.

Many discrete problem behaviors are caused by common antecedents (demographic, personal, familial and community-related). Successful prevention of those behaviors (i.e., unprotected intercourse and drug use, in the case of HIV/AIDS) will only result from interventions that address the antecedents. Too many prevention programs, Dryfoos notes, address only the problem behavior and not the root causes of it.  

Eleven common program components emerged from Dryfoos' analysis of the reported practices in successful intervention programs. The first two, she states, have the widest application. The 11 components are:

- intensive, individualized attention.
- community-wide, multi-agency collaborative approaches
- early identification and intervention
- locus in schools
- administration of school programs by agencies outside schools
- location of programs outside schools (which can reach out-of-school youth)
- arrangements for training
- social skills training
- engagement of peers in intervention
- involvement of parents
- link to the world of work

64 Dryfoos, pp.4-8.
65 Ibid., pp. 228-232.
Some combination of these 11 components were found in a variety of successful prevention programs; few, if any, programs incorporated all of them. The first two, however—intensive individualized attention and community-wide multi-agency collaborative efforts—were cited by Dryfoos as having the widest application.

Each of the 11 program components can be part of a comprehensive HIV/AIDS prevention program. Intensive, individualized attention to each young person involved in the HIV/AIDS intervention would help ensure continued involvement in the program and bolster a sense of self-worth. Community-wide, multi-agency collaboration would allow agencies to combine talent and resources to provide a comprehensive package of education and services to young people. Early identification and intervention means starting in the primary grades to provide a foundation of HIV/AIDS education and skills-building.

Locus in schools and administration of school programs by agencies outside schools indicates that schools are an excellent place to provide HIV education and that innovative administrative arrangements are possible. Most high schools already address HIV/AIDS to some extent, but most programs could be improved and expanded. Not all successful prevention programs, however, must be located in schools. Community-based organizations and youth-serving agencies should implement HIV/AIDS prevention, as they are more likely to reach out-of-school youth and youth in other high-risk situations.

Providing training to staff and volunteers who provide youth with HIV/AIDS prevention education is critical, as they must be prepared to address a wide range of concerns and topics.

Social skills training that helps adolescents develop the negotiation and assertiveness skills necessary for abstinence or safer sex negotiation are a critical component of HIV/AIDS prevention education. Peer educators who can impart information, model skills and help change peer norms are excellent resources for HIV/AIDS prevention programs. Evidence suggests, however, that it is the peer educators themselves who benefit the most from these programs, probably because of the intensive, individualized attention they receive.

Involving parents in HIV/AIDS education allows them to understand and help shape the program. Learning in the program can be reinforced in the home. Lastly, linking HIV/AIDS prevention education to the world of work stresses that HIV/AIDS education cannot take place in a vacuum. Young people need options and a belief in the future in order to feel invested enough to protect themselves.

Dryfoos identified six major points that prevention experts agree upon.

- There is no single program component that by itself can alter the outcomes for all children at risk.
- High-risk behaviors are interrelated; prevention programs should have holistic goals.
- A package of services is required within each community.
- Interventions should be aimed at changing institutions rather than at changing individuals.
- Early intervention is critical.
Continuity of efforts must be maintained; one-shot programs have no effect.66

All six precepts are relevant to HIV/AIDS prevention. First, there is no one magic approach that will prevent the spread of HIV among adolescents. Different populations and communities have different needs. Second, because the sexual behaviors that put young people at risk for HIV/AIDS are the same as those that can lead to unwanted pregnancy and sexually transmitted diseases, an interrelated approach is useful. Alcohol and other drug use can lead to HIV infection and may be a symptom of larger problems.

Third, HIV/AIDS education requires a package of services that include education, skills-training, health care, drug/alcohol treatment and access to condoms. Fourth, interventions that work at a larger environmental level for teens are as important as interventions that work at the individual level of behavior change. Making condoms available in schools or forging useful collaborative relationships among youth-serving agencies are examples of that type of intervention.

Fifth, early HIV/AIDS interventions should begin years before young people are faced with important decisions regarding sexual activity and drug use. Age-appropriate information and skill-building components are essential. Sixth, HIV/AIDS education must be ongoing, not a one-shot program, and should be supplemented with access to medical and social services.

Model HIV/AIDS Prevention Programs

There are many HIV/AIDS prevention programs currently in place in the United States in a wide variety of settings. Some have a few of the critical components for success as outlined by Dryfoos, others have none, and a very small number have several. Very little evaluation of any of these programs has been reported as yet. In this section, three programs are highlighted as models either because they have many of the components indicated for success and/or because they have been evaluated.

HIV Center for Clinical and Behavioral Studies

The HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute has devised a model comprehensive intervention program that has been implemented and evaluated in several agencies in New York City that serve either runaway adolescents or gay/bisexual young men.

The four intervention components are: 1) activities focused on acquiring general knowledge of HIV/AIDS through a variety of creative media; 2) training in coping skills; 3) access to health care and social services; and 4) individual counseling sessions.

In 1991, the Director of the Center, Mary Jane Rotheram-Borus, reported her study of the impact of the intervention on the high-risk behavior of 145 runaways at residential shelters in New York. Young people in her program were exposed to up to 30 sessions focusing on general knowledge of HIV/AIDS, coping skills, access to resources and individual counseling to reduce barriers to safer sexual activity. The young people who received the comprehensive intervention reported an increase in condom use and a decrease in high-risk behavior.67

66 Ibid., pp. 233-234.
The same intensive HIV/AIDS intervention was provided to young gay males 14-19 (most of whom are African-American or Hispanic) After one year, 57 percent of program participants reported increased condom use.68

Contact: Mary Jane Rotheram-Borus, Director, HIV Center for Clinical and Behavioral Studies, Adolescent Prevention Studies Unit, New York State Psychiatric Institute, 722 W. 168th St., P.O. Box 29, New York, NY 10032. (212) 740-7320.

Youth and AIDS Project

The Youth and AIDS Project (YAP) is a combined research and service effort, housed in the Department of Pediatrics at the University of Minnesota, focusing on gay and bisexual males ages 14 to 21. Participants are reached through referrals from school personnel, traditional youth-serving agencies, gay/lesbian youth support groups, peers and street outreach workers. About 100 young people go through the program each year. Some of them are high-functioning college students while others are living on the street, engaging in survival sex.

Each participant in the program begins with a two-hour meeting with a case manager. During that time, a range of issues are discussed, including: gay/bisexual sexuality issues, HIV knowledge, family dynamics, alcohol and other drug use, housing, schooling and HIV risk assessment. The purpose of the initial two-hour session is to obtain a clear picture of the entire situation the young man is facing, to initiate appropriate referrals and to provide correct HIV information.

The second step of the program involves a one-and-a-half-hour peer group session, designed and led by "graduates" of the program who have received intensive training. In the session, the young men talk with each other, discussing issues related to HIV/AIDS, sexual orientation, and alcohol/drug use. They have the opportunity to examine their own values and begin to understand that safer sex is an option. Staff of the program note that many of the program participants have preconceived notions about peer norms—they assume, for instance, that condom use is rare. The group discussions help change their opinions about condom use. The peer education program also focuses on negotiating safer sex with partners and allows participants to develop "key messages" about safer sex that they can apply in the future.

Three months after the initial meeting with the case manager, and after the peer group session, participants meet one-on-one with the case manager again. Initial data from YAP indicates that after participating in the program for three months, the young men reported a sharp increase in consistent use of condoms during sexual intercourse.69

Both anonymous and confidential HIV counseling and testing is offered through YAP once a week. Program participants who request testing receive pre- and post-test counseling in sessions separate from the two-hour meeting with the case manager.

For young men who are HIV positive, YAP has a case management component that helps provide medical and emotional support services.

The Door

The Door in New York City is widely regarded as the prototype of an integrated comprehensive service model for adolescents. It serves 6,000 adolescents ages 12 to 21 every year. The 17-year-old facility incorporates HIV prevention education and services throughout its program of Education, Creative/Physical Arts, Adolescent Health Center, Mental Health Counseling and Mileu (socializing/socialization).

Every young person who uses The Door for two months is required to undergo a physical exam, sexual health/awareness counseling and a HIV personal risk assessment. The Door offers confidential HIV antibody testing with pre- and post-test counseling and recommends adolescent-sensitive sites in New York City for anonymous testing.

The staff health educator interacts with every program provided for Door participants, such as GED preparation, creative arts, athletics and those designed for young mothers, young fathers and gay/lesbian/bisexual youth. Messages are tailored to those particular groups' needs and concerns.

The Door also provides youth the opportunity to discuss and practice the skills necessary to negotiate safer sex practices through small group sessions focusing on dating relationships.

Lastly, all staff at The Door receive ongoing HIV training.

Contact: Sylvia Muniz, Supervisor of HIV Prevention, The Door, 121 Avenue of the Americas, New York, NY 10013 (212) 941-9090 (ext. 271).
STATE POLICY STRATEGIES

The spread of HIV/AIDS among youth is closely linked with other negative outcomes of risk-taking behaviors as well as broad social problems: drug abuse, unwanted pregnancy, sexually transmitted disease epidemics, school failure and homelessness. In each case, successful prevention strategies will focus not merely on the identified problem, but must strike at the underlying behaviors and environments that foster them. Effective prevention programs must deliver user-friendly combinations of information, skills and health, mental health and social services. Fighting the spread of HIV in the adolescent population is possible through:

- Collaboration within communities and state agencies
- Comprehensive school health education and services
- HIV/AIDS education in non-school settings and to youth in high-risk situations
- Health promotion campaigns and social marketing of condoms
- Meaningful program evaluation
- Testing and counseling of adolescents.

While some strategies can be implemented by state agencies—such as state-wide public education campaigns—most of the preventive programs and services will be implemented at the local level. The following policy strategies, therefore, primarily address the question: How can state government assist local communities in preventing the spread of HIV among adolescents and in preparing adolescents for a healthy adulthood?

Create Mechanisms for Encouraging Collaboration Within Communities and State Agencies

Barriers between local agencies that provide services to adolescents and competition for limited funds should be reduced or eliminated. Historically, federal, state and local governments have dealt with adolescent problems categorically. Regulations and grant-making procedures often preclude rather than facilitate collaboration between programs, or make the delivery of multiple services at a single site impossible. Federal or state regulations defining eligibility, accountability, organizational structure, facilities, client population and staffing patterns can all become barriers to cooperation at the local level.

In addition, programs are being asked to do more with less. Limits on allowable expenses as well as insufficient funding affect program flexibility and staff time available for collaboration. By establishing and funding a structure for local collaboration, states potentially could save money by helping communities avoid duplication of services and increase the effectiveness of their interventions.
A "commission," "working group," or "coordinating council" should be created for adolescent programs/service administrators in state health, education, human services and juvenile justice agencies to share information and develop joint strategies. Since many of the barriers to local collaboration originate at the state or federal level, the effort to sort through the problem and develop creative solutions must begin there. In authorizing this entity, legislation should include provisions modeled after Title III Sec. 402 of S. 3088, the Comprehensive Services for Youth Act introduced for the first time by Senator Edward Kennedy in 1992.

That section would amend the Augustus F. Hawkins Human Services Reauthorization Act of 1990 by including the following mandate for the Federal Council on Children, Youth and Families:

"(6) identify program regulations, practices, and eligibility requirements that impede coordination and collaboration and make recommendations for their modifications or elimination;

"(7) develop recommendations for creating jointly funded programs, unified assessments, eligibility, and application procedures, and confidentiality protections that facilitate appropriate information sharing; and

"(8) make recommendations to Congress concerning legislative action needed to facilitate the coordination of education, health and social services for in-school and out-of-school youth."  

The Comprehensive Services for Youth Act, which targets youth at greatest risk of HIV and other negative consequences of behavior, would also foster statewide coordination of services by providing grants to states. State grants would be used for coordinating and delivering comprehensive health, mental health and social services through a system of school-based, school-linked, or community based youth centers that are planned and administered by local collaborative partnerships. State planning grants would also be available to establish necessary administrative mechanisms, conduct needs assessments, develop program goals and objectives and assist with strategic planning.

**Support Comprehensive School Health Education and Services**

Adolescents do not experience their problems in isolation from other problems. The young woman who needs help to pass her English class may also be depressed, engaging in unprotected sexual intercourse, experiencing major conflicts with her parents and using cocaine between classes. "Any effective prevention or intervention must have the capacity to access and analyze the entire universe of an individual adolescent's life experiences...and develop appropriate responses when problems are identified," notes adolescent medical expert Dr. Robert Johnson.  

The current trend in health education is toward "comprehensive school health," which encompasses the whole school community. Food service, physical education, counseling, school nurse offices and school-based or -linked health centers all cooperate in providing students and staff members with health education and a healthy environment. Comprehensive school health recognizes the necessity of health for learning to occur, and the need for education in equipping

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70 U.S. Congress, Senate, Comprehensive Services for Youth Act, 102nd Congress, 2d sess., S.3088, 1992.

71 Robert Johnson, testimony.
adolescents for a healthy future. This link between environment, health services and health education is a cornerstone in any prevention effort.

**Bolster school HIV/AIDS education**

To be effective in helping students modify risk-taking behaviors, HIV/AIDS education must incorporate elements of all three learning domains—cognitive, values/affective and skills-building. While every state currently either requires or recommends HIV/AIDS education through law or policy, provisions of these policies vary greatly in content and specificity.

An analysis of 34 states' HIV/AIDS education programs, curricula and guidelines by the Sex Information and Education Council of the U.S. (SIECUS) reveals that very few deal with feelings or the variety of skills needed to avoid or reduce risk of HIV infection. Only 27 teach refusal skills; 15 teach assertive communication; four teach condom use and sexual limit-setting skills, and only three teach students how to evaluate risky sexual behaviors. All states follow Centers for Disease Control and Prevention curricula guidelines promoting strong messages of sexual and drug abstinence, with an emphasis on lifelong monogamy within marriage.

SIECUS' recommendations to improve state HIV/AIDS education programs include:

- enactment of legislation that require developmentally-appropriate and properly sequenced HIV/AIDS education program for all grades K-12.
- HIV/AIDS education integrated as part of comprehensive health education that provides direction or program implementation and evaluation, including:
  - curriculum recommendations
  - required teacher preparation and certification, and
  - evaluation criteria to determine program effectiveness;
- state monitoring to ensure that state mandates are enforced at the local level; and
- inclusion of parents as active participants in all stages of program development and implementation.

In addition, one of the most important factors in developing or maintaining effective HIV/AIDS education programs for adolescents is involving youth in both planning and implementation of programs. Whenever state policy designates an advisory board or committee, adolescents should be represented.

**Support school-based and school-linked health centers**

School-based and school-linked health centers (SBHCs) have been termed "the most promising recent innovation to address the health and related needs of adolescents." Located in or near schools, these centers are uniquely positioned to offer a range of health services to young people. They are accessible, comprehensive, improve compliance and facilitate follow-up, have

72 Britton, De Mauro and Gambrell, p. 24.
73 Britton, De Mauro and Gambrell, pp. 11-26.
74 U.S. Congress, Office of Technology Assessment, Adolescent Health--Volume I, p. 31.
support of their communities, address the problems of early, unprotected sexual activity and involve parents.75

Core SBHC services should include a range of necessary HIV prevention education and services, including: risk reduction counseling, sexual health assessment, HIV counseling and testing, access to condoms and alcohol and other drug use screening and treatment referral.

States should consider supporting SBHCs by approving start-up funds for demonstration projects in schools with populations at high risk; providing operating funds for established centers; establishing a state office to provide technical assistance and training for health center staff and school staff; or providing incentives to teaching hospitals, community health centers or other primary care providers to collaborate with schools in establishing health centers.

Legislation could also streamline access of SBHCs to existing sources of federal and state Medicaid (including Early Periodic Screening Diagnosis and Treatment), Title V or other programmatic funds. In most states, this access to funds is hampered by eligibility requirements, reimbursement procedures and rates, burdensome and costly paperwork and student concerns about confidentiality. As an increasing number of states move toward instituting a system of Medicaid managed care, SBHCs' relationship to and reimbursement by private and Medicaid health maintenance organizations needs clarification.

Support local schools' option to implement condom availability programs

Many school personnel, public health officials and policymakers are suggesting that high schools make latex condoms available to students who engage in sexual intercourse. They reason that schools are uniquely positioned to provide comprehensive HIV/AIDS prevention through two-part health and sexuality programs that include education and access to barrier methods that protect against disease and unintended pregnancy.76

Although states differ in the extent of control they delegate to the local school, school boards are generally given broad authority to conduct activities or programs and expend funds to meet the needs of their students. Increasingly, states are encouraging "school-based management" as a strategy for improving the quality of solutions to local school problems. A condom availability program would, unless otherwise prohibited by law, generally be considered a policy choice within the authority of a school board to make.

As of this writing, some states have laws explicitly limiting or prohibiting condoms in schools. Several states, including Louisiana, Michigan and South Carolina, prohibit the distribution of contraceptive drugs or devices on school grounds. Other states restrict or prohibit a particular method of distribution, such as through school health centers or vending machines. Arkansas has prohibited the use of state funds to make condoms or other contraceptives available in schools, although federal and local funds are not similarly restricted.

These restrictions need to be repealed, so that communities can implement programs directly responsive to the needs of their youth. Making condoms available within schools does not introduce an otherwise unobtainable commodity to students. Rather, it expands the range of sources and facilitates teens' access to an important health aid. A majority of adults understand

76 Center for Population Options, Condom Availability in Schools.
that social endorsement by adults and society is a critical factor in normalizing condom use for teens. Polls indicate strong support for giving teens access to condoms in school.\footnote{77 The Roper Organization, Inc. "AIDS Public Attitudes and Education Needs" prepared for Gay Men's Health Crisis, New York, NY, 1991; Stanley E. Ealm, Lowell C. Rose and Alec M. Gallup, "24th Annual Gallup Poll/Phi Delta Kappa of the Public's Attitudes Towards the Public Schools," September, 1992. The Roper poll reports that 64 percent of adults say condoms should be available in schools. The Gallup poll indicates that support for condom availability has grown to 68 percent.}

Support Provision of HIV/AIDS Education in Non-School Settings and to Youth in High-Risk Situations

Out-of-school youth will not have access to school-based or school-linked health centers, school condom availability programs or school-based HIV/AIDS education, yet they are at greater risk than many of their peers who spend a large portion of their day in the classroom. Multiple strategies are required to reach these young people who may lack contact with any supportive adult.

Standard interventions might not be adequate for youth in a state's foster care system due to confusion about where primary responsibility for HIV/AIDS education lies. Foster parents, caseworkers, the school system and biological parents all have moral or legal responsibility for these young people.\footnote{78 D.F. Polit, "Sex Education and Family Planning Services for Youth in Foster Care," Family Planning Perspectives Vol.19. No.18, 1987.}\footnote{79 U.S. Congress, House, Select Committee on Children, Youth and Families, Decade of Denial, p. 140.} But sensitive issues such as sexuality, drug use and HIV/AIDS may be avoided or forgotten unless expectations and accountability are clearly understood.

States should consider strategies to provide incarcerated and detained youth with the information, medical services, and resources necessary for behavior change, including access to latex condoms. Damon Marquis, Director of Health Education of the National Commission on Correctional Health Care, submitted testimony to Congress stating that many incarcerated or detained youth have not received the benefit of conventional health educational resources because they were out of school and/or homeless prior to being placed in juvenile facilities. For others, this may be the only time a proactive health education program is offered in any setting. This is an excellent opportunity to provide the youth with the information and resources necessary to make vital behavior change.

Protecting incarcerated youth from abuse and assault is another vital strategy for reducing their risk of HIV infection. Separating adult from youthful offenders, addressing issues of overcrowding, and providing for alternative sentencing are not normally seen as HIV/AIDS prevention measures, but could in fact reduce the risk of HIV exposure within the juvenile justice system.

Provide funding, training and support to community-based organizations that focus on youth in high-risk situations

Community-based organizations are often the only institutions that provide out-of-school or unemployed youth with the continuity and relationship needed for effective HIV/AIDS prevention education. All state-funded community-based programs should be encouraged or required to provide some form of HIV/AIDS prevention education to their clients or members.
In considering grant proposals, states could give priority to those with plans to provide HIV/AIDS prevention services in collaboration with other community-based groups, or to train their own staff to work with at-risk clients.

States should also ensure that an adequate share of HIV prevention funds are channeled to organizations that reach youth at highest risk, including youth of color, immigrant youth and alcohol- and drug-using youth. The National Minority AIDS Council states that "targeted communities receive an inadequate fraction of HIV-related funds channeled through state and local health departments because of 1) general neglect of minority community based organizations; 2) inappropriate mechanisms for determining need; 3) an unwillingness to expand the service delivery system to include disenfranchised people and 4) absorption through government administrative costs."

Support and service programs for lesbian, gay and bisexual youth have been started in many areas around the U.S. Over 170 organizations provide counseling, emergency shelter, medical care, support groups, social events and other services to these young people. Support funding would allow these organizations to continue to provide these critical services.

Some national organizations are advocating a licensing requirement for all HIV prevention providers as a way to ensure the accuracy of information being provided. Community-based organizations that work with youth in high-risk situations have expressed concern, however, that such a requirement would add another layer of bureaucracy between service providers and the communities in need, and that the standards set and training required might not be sensitive to the needs of the communities they serve. Furthermore, it is unclear how licensing standards would address the issues of skills-development and access to services, which are necessary components of programs seeking behavior change. A licensing requirement might prevent many such groups from participating in HIV/AIDS prevention efforts, and could mean that the people they serve would receive no HIV/AIDS interventions.

Support Health Promotion Campaigns and Social Marketing of Condoms

States could authorize and fund public health departments to participate in HIV/AIDS prevention mass media campaigns similar to those promoting seat belt use, fire safety, and responsible use of alcohol. Funds could be allocated to produce and distribute materials suitable for a variety of media, or to purchase materials from another public or private source, that are targeted specifically for adolescents.

States could also consider providing grants to community-based organizations that serve youth in high-risk situations to conduct targeted "social marketing" campaigns. "Social marketing" means applying commercial marketing techniques to promoting healthy behavior. This approach includes mass media advertising campaigns to motivate positive behavior change; making needed health products more available and affordable by distributing them through commercial networks at low-cost; promoting health products at the point-of-purchase; and involving the business community to generate broader involvement and social support for the desired outcome.

The first social marketing program targeting condom use in the United States is sponsored by Population Services International (PSI) in Portland, OR. The goal of the program, which began in August, 1992, is to help reduce the spread of HIV among teenagers at highest risk by increasing

the correct and consistent use of latex condoms among youth engaging in sexual intercourse. The PSI model program, called Project ACTION, involves an intensive radio and television campaign promoting condom use; providing condoms at reduced cost through vending machines in locations teens frequent; community interventions to teach sexual negotiation and relational skills; and a thorough outcome evaluation study.82

**Require and Fund Meaningful Program Evaluation**

States cannot afford to waste scarce public funds on strategies that do not work, and policymakers prefer to fund only those types of programs which have been proven effective in changing behavior. Unfortunately, there is currently very little specific evaluation data on HIV/AIDS prevention programs.

"Many programs with a great deal of potential have not been evaluated because they are operated by administrators whose priorities are elsewhere [e.g., providing services]. Unless their funding requires evaluation, there is no incentive to conduct research."83 Tying receipt of state dollars to meaningful evaluation or requiring that a portion of the budget be dedicated to evaluation would increase the amount of data available. States should require that programs establish goals and objectives and plans for measuring achievements along with grant requests.

Because prevention of HIV infection, like prevention of pregnancy, is so difficult to prove, most evaluations would focus on improvements in knowledge, attitude changes, intentions to change behavior, or actual behavior change. Nevertheless, so many factors in a young person's life and so many variables in every program's design could affect risk-taking behavior that teasing out which ones caused behavior change can be nearly impossible. Likewise, if program outcomes were not good, it would be equally difficult to determine definitively which factor—or combination—caused the failure. Yet, as more programs evaluate their procedures and outcomes, they contribute to the general body of knowledge from which conclusions can be drawn and better judgments made about the likelihood of a program's success.

Long-term outcome evaluation is expensive, but the data generated would be of great value to policymakers and program designers in the future. This kind of research, however, is beyond the scope of virtually all school or community-based programs, without assistance from a university or professional research agency.

**Support the Proper Use of Testing and Counseling of Adolescents**

HIV antibody testing and counseling policies evoke debates about coercion, confidentiality, and government intrusion in personal lives. For adolescents, as well as for adults, counseling and testing is most often a gateway to medical services and early intervention. Although counseling and testing may seem to provide opportunities for education and suggest the recognition of personal risk that could motivate behavior change, counseling and testing are not prevention strategies. Counseling and testing strategies do not contain the components necessary for a good prevention program. For many individuals, testing negative for HIV only confirms a lack of personal vulnerability and lack of need to change behavior. In addition, there are those who take the test but fail to return for the results.

82 Julie Convisser, Director of Project ACTION, personal communication with author. February 17, 1993.
83 Dryfoos, p. 240
Counseling and follow-up issues

As with adults, there are both benefits and risks for adolescents being tested for the HIV antibody. For adolescents, emotional maturity, cognitive development and access to medical and social support systems are crucial issues to consider. Developmental characteristics may influence adolescents' attitudes about being tested and may affect their responses upon learning the test results. Teens' feelings of social isolation or connectedness influence their responses to being tested. Teens may feel very vulnerable both during the testing process and after the results are learned. Guidelines for appropriate pre- and post-test counseling of adolescents are available and should be followed.

Experts agree that access to appropriate medical and supportive social services is critical for young people who test positive for HIV. They cannot be expected to seek out medical care and emotional support on their own; they must be guided to those services.

Parental consent/confidentiality issues

Only a few states currently have statutes that expressly authorize minors to consent to or receive HIV antibody testing without parental consent. These laws vary with respect to parental notification requirements; some give providers discretion and one requires parental notification if the test is positive.

Voluntary HIV testing and counseling without parental consent should be available to all adolescents, especially those at high risk of infection. It is important, however, to ensure that legislation giving minors that right is not predicated on naming HIV an infectious, contagious or communicable disease that would then trigger mandatory reporting and partner notification, which would discourage adolescents from being tested.

CONCLUSION

This generation of young people is at risk for contracting an always fatal disease that can be prevented. State and local agencies and organizations must cooperate to fund, implement and evaluate HIV/AIDS prevention programs that are comprehensive in scope and targeted appropriately. While some young people are at greater risk than others, all teens need the information, skills, materials and services that will allow them to make healthy decisions now—and in the future, as adults.

In 1992, 80 bills were introduced in state legislatures in the area of HIV/AIDS prevention and education; six were enacted and six were vetoed. Of the bills that were signed into law, three require that abstinence instruction be emphasized in any kind of school sex/health program.87

There are no quick fixes to the adolescent HIV/AIDS problem. The kind of strategies, as outlined above would be most useful in effecting real change in young people's lives and behaviors. These program components will go beyond merely providing information, whether it is abstinence-focused or not. Instead, effective legislation will truly meet the developmental, social and environmental needs of today's young people, empowering them to remain free of HIV and AIDS.

BIBLIOGRAPHY


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