Public Policy Implications of HIV/AIDS in Adolescents

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The relationship between the HIV/AIDS epidemic and the adolescent population in the United States has not received sufficient attention. Not only are an increasing number of adolescents of both sexes becoming infected, but a great many adults acquire the infection, often remaining asymptomatic, during their youth. Thus, the interface of the education and health systems is of central importance in preventing HIV/AIDS infection and subsequent death. This problem adds an urgency to making changes in school-linked health services previously addressed in the Spring 1992 issue of The Future of Children.

For those youth who are in school continuously and for those who are there intermittently (most school dropouts), the schools represent the most practical and best locus to deal with what, unfortunately, remains basically a matter of life (prevention) or death (infection). In this context the community need is to protect children and others from the epidemic by educating adolescents about high-risk sexual behaviors and their consequences and about measures to reduce the risk of infection and death (including programs that involve education about and distribution of condoms). This is in direct conflict with those who do not want matters of sexuality and reproduction addressed outside family and religious venues because of concerns about promoting promiscuity, denigrating religious beliefs, or displacing family responsibilities. The authors of this article attempt to reduce or resolve aspects of this conflict by analyzing available evidence on some of the important concerns that are inhibiting the initiation and implementation of life-saving, effective prevention programs. They also suggest changes in existing policies and programs at local, state, and national levels which might further reduce the risks of infection and death among this population of children and improve their health care generally.

The impact of HIV on adolescents is different from its impact on other age groups or communities. Adolescents are neither large children nor small adults. From an epidemiological standpoint, the pattern of HIV infection in adolescents differs from that of HIV infection in children or adults. In addition, adolescents are in a stage of social, physical, and psychological development which requires unique program and treatment strategies.

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Characteristics of the HIV Epidemic Among Adolescents

Adolescents Are Not Big Children
The route of HIV infection among children is almost always vertical from an infected mother. HIV-infected young children have a shorter survival time than adolescents on average.7 HIV prevention programs designed to address perinatal infection should be aimed at sexually experienced young men and women, the pool of potential parents. A small but growing proportion of long-term surviving infants infected with HIV are now reaching adolescence. Specific educational and health care services need to be developed to support these young people as they progress from childhood to adolescence.

Adolescents Are Not Small Adults
HIV-infected adolescents differ also from their adult counterparts. A greater proportion of infected teenagers acquire HIV through heterosexual transmission as compared with adults; a higher percentage of teenage patients are asymptomatic, becoming symptomatic with HIV-related illnesses during adulthood; and a higher percentage of infected youth are black or Hispanic as compared with adults. There are also unique legal issues that exist for adolescents regarding consent for HIV testing and treatment, and limited access to treatment, including clinical trials.4 Disclosure of HIV serostatus to partners and parents is particularly difficult for young people as well.5 Finally, there are cognitive differences which affect the acquisition and application of knowledge, information, and skills.6

Health care providers often assume that HIV testing and related services require parental consent, but laws vary from state to state. While every state has laws protecting the confidentiality of medical information, this protection is not necessarily extended to minors. Depending on such circumstances as whether the condition presents imminent danger to the young person or others and the nature of the treatment or services (for example, mental health, drug use, hospitalization), parental involvement may or may not be required. Some states explicitly require notification of parents when an HIV test result is positive for a minor, while others permit notification under other laws related to medical treatment for minors.7

Unique Needs of Adolescents
The World Health Organization estimates that half of the 14 million people in the world who are infected with HIV were infected between the ages of 15 and 24. In the United States, the three largest national studies of youth in the military, college health services, and the Job Corps report overall HIV infection rates of 1/1,000, 2/1,000, and 3/1,000, respectively. The rates vary enormously by region, gender, and ethnic/racial groups. The fastest growing rates of HIV are no longer reported from the large coastal cities known to be hard hit in the early 1980s. Now, mid-Atlantic states are reporting the greatest increase in HIV rates among young women, according to the latest study of female Job Corps students. Studies of youth living in high-risk situations, such as those in a shelter in New York City, report much higher rates, up to 160/1,000 for older adolescent males. In several recent studies, young women are now becoming infected at a faster rate than either young men or adult women. For example, in the most recent report from the Job Corps, female students had HIV rates twice as high as those of their male counterparts. In Asia, where HIV is spreading quickly, teenaged girls ages 15 to 19 are reported to have the highest rates among women. AIDS cases in adolescents are not a good indicator of the extent of HIV infection because most teenagers with HIV have not been tested and because it takes, on average, 10 years for people with HIV to be diagnosed with AIDS.

From a treatment perspective, assessment of individual social, psychological, and physical development is essential before specific treatment plans can be developed. This requires understanding of adolescent development and addressing barriers to care. In addition, the health assessment—including a social and medical history, physical examination, and laboratory evaluation—of teenagers dif-
fers from that of young children and adults. Special attention needs to be paid to this age group with respect to the presenting signs and symptoms of HIV-related disease, types of immunization given, the dosage of medications, and the range of normal values for laboratory testing of immune function, anemia, and liver function. In summary, there are unique epidemiologic features of the HIV epidemic among youth, in addition to special legal and programmatic requirements for age-appropriate care of adolescents.

**Adolescent Risk Behavior**

All adolescents in the United States of America are affected by the HIV epidemic, whether infected or not. Virtually all adolescents have heard about AIDS, most now have heard about someone with HIV or AIDS, and an increasing number know of someone with HIV, whether it be a family member, neighbor, friend, adult, or national celebrity.

According to the 1990 Youth Risk Behavior Survey administered by the Centers for Disease Control (CDC) and Prevention, the median age of reported first intercourse is 16.1 years for young men and 16.9 years for young women. One-third of the young men and 20% of the young women initiate intercourse before the age of 15. Among 9th- to 12th-graders, 19% report having had four or more sexual partners during their lifetime. Concomitant with these rates of sexual activity are the highest rates of sexually transmitted disease, such as gonorrhea, syphilis, chlamydia, and herpes, of any sexually active age group. Each year between 2.5 and 3 million young people become infected with a sexually transmitted disease. Therefore, most adolescents are at risk for acquiring HIV during their teenage years because HIV has now spread to all 50 states and much of the sexual intercourse in which adolescents are engaging is unprotected.

Age-appropriate health education programs for adolescents should be built on the premise that teenagers need to learn and know about their own bodies. At the same time, they should develop positive views of sexuality and intimacy in addition to knowing about the unwanted consequences of sexual intercourse, such as sexually transmitted disease or unplanned pregnancy. Practicing new skills and experimenting to learn personal limits are natural parts of this stage of development.

The risks associated with normal adolescent development can be managed only through the acquisition of explicit knowledge and the modulation, if not the modification, of one’s behavior. So, it is not only the consequences of HIV infection among adolescents that make this topic of particular importance to policymakers, but also the nature of the debate it inspires and the strategies it requires.

Mixed messages about human sexuality generally, and its relationship to adolescent development specifically, make it difficult for public policymakers to navigate both the complexity and the controversy associated with HIV transmission and adolescent behavior. Whether this epidemic is seen from a health or education perspective, the threat of HIV to adolescents requires an acknowledgment of adolescent sexuality and risk behavior, and impugns the practice of making concessions and compromises to assuage controversy.

**HIV/AIDS Education**

**Contrasting Styles of Health Education**

In the health care community, education is provided one on one, usually in a medical office setting. When health education occurs in schools, presentations are conducted in large groups, and seldom are they conducted or even influenced by health care professionals. This is true even in schools with school-based health clinics. Nurses, nurse practitioners, physician assistants, and health aides constitute the vast majority of health care providers who are visible in school settings. The providers, as a rule, are not involved in health education curriculum development or program design.

The HIV/AIDS epidemic and its implications for the adolescent community justify a reassessment of past practices and make a compelling argument for ending the isolationism of both the health and
education sectors. Strategies to prevent the further spread of the HIV virus among adolescents are more likely to succeed if they draw upon the resources, knowledge, and talent possessed by both health and education professionals. The recommendations presented in this article reflect a bias toward collaborative program planning and development, with suggestions of opportunities and strategies for partnership at the local, state, and federal levels.

**What States Require**

All 50 states either “require or recommend” HIV/AIDS education by legislation or policy, according to a study conducted by the Sex Information Education Council of the United States (SIECUS).¹³ Ninety percent of those states . . . have guidelines for the discussion of abstinence, though few if any have guidelines that . . . require an explicit discussion of risk behavior and modes of transmission.

These numbers speak to the prevalence of HIV/AIDS education programs but not to the quality of the programs themselves.

All 50 states have also established HIV/AIDS Advisory Committees, but only 44 include physicians or medical personnel, and none require the involvement of HIV experts. Even where school-based or school board advisory committees exist, the state model offers little in the way of guidance or support for extending such committees to include HIV/AIDS and adolescent behavior experts. The issue, then, is not whether states have recognized the need for education but, rather, the quality of the education that is being offered.

**What States Provide**

Nationally, and even internationally, AIDS prevention education materials are being developed rapidly. The CDC maintains a resource listing of HIV/AIDS educational materials, as do several other national organizations concerned with this issue, including the Council of Great City Schools, SIECUS, and the National School Boards Association. Some state education departments or health departments maintain a data base on educational materials. There is no dearth of educational materials, though the quality and appropriateness of materials varies from community to community. New York City established a program that involves adolescents in the development of peer education materials for AIDS prevention. This program, called Be Active in Self Education, provides groups of young people with small amounts of money (up to $2,500) to develop educational materials, from newsletters to classroom videos, for use in their own schools with their own peers. It has...
proven effective both in involving young people in group educational activities and in producing a myriad of innovative AIDS prevention educational materials for use in the New York City public schools.

A close review of the programs that currently exist across the country reveals significant shortcomings. Curricula tend to concentrate on the scientific and biological aspects of HIV infection—cell biology, DNA, RNA, and the nature of a retrovirus—avoiding the practical implications and specific details of HIV transmission. There is frequently an overemphasis on abstinence as a prevention strategy without a balanced presentation of human sexuality and safer sex practices. Ninety percent of those states that have HIV/AIDS curricula have guidelines for the discussion of abstinence, though few if any have guidelines that specifically address and require an explicit discussion of risk behavior and modes of transmission. Programs lack instruction about sexual responsibility and decision-making skills. They avoid explicit instructions for adolescents on condom usage, and insufficient staff development is provided to support program implementation. There is a failure to monitor and assist with program implementation, and, as a consequence, school districts develop HIV/AIDS curricula and continue to use materials even when the information contained within them is seriously out of date.

Even when sexuality and AIDS education are being addressed, the grade level at which schools begin to discuss these issues is often after the point by which many adolescents have already begun to engage in behaviors that place them at risk of infection.

Because condoms are less likely to be used by people who perceive them to be ineffective than by those who consider them to be highly effective, the argument undermines the goal of preventing the spread of HIV infection.

Too often efforts to implement HIV/AIDS prevention education become battles, and they are waged in emotional terms rather than on the basis of empirical evidence of medical facts and adolescent development and behavior.

In the debate that has raged in cities across the country concerning condom availability, for example, two issues always emerge: the effectiveness of condoms in preventing the sexual transmission of the AIDS virus and the allegation that condom availability encourages sexual promiscuity.

Myths and Facts

The following statements are examples of arguments employed by people who oppose explicit sex and HIV/AIDS education, as well as school-based condom availability. In each instance, a response is presented that is based on an appreciation and understanding of adolescent development and scientific studies involving young people.

“Condoms Don’t Work”

Condoms are not 100% effective, but effectiveness is most often determined by how the condom is used, not by the quality of the product itself. Succumbing to the argument that condoms are not 100% effective and should therefore not be promoted as a prevention strategy is tantamount to telling people who ride motorcycles not to use helmets because wearing a helmet doesn’t protect completely from head injury in the case of an accident.

“Condom Availability Encourages Sexual Intercourse”

The second argument against condom availability asserts that such a policy promotes sexual intercourse and condones sexual promiscuity among adolescents. In 1987, Switzerland introduced a public health campaign targeted to young adults that promoted condom use as a major means of HIV/AIDS prevention. From January 1987 until October of 1991, self-reported consistent condom use among
persons aged 17 to 30 years increased from 8% to 52% in association with the campaign. The proportion of adolescents aged 16 to 19 years who had sexual intercourse did not increase over that period. 18

“Talking About Sex Leads to Sex”

Studies from other western industrialized nations show that, while young people have the same age of first intercourse elsewhere as in the United States, those nations with comprehensive services and explicit sex education have lower rates of unintended pregnancy and abortion than the United States. 19

Divide and Conquer: A Failed Strategy

Good Kids–Bad Kids Versus All Kids

In practice schools have shied away from topics that provoke community debate, and to the extent that they do develop programs that deal with adolescent sexuality and risk taking, the programs are targeted to a subset of the school population. We see evidence of this strategy in programs that deal with so-called high-risk youth: programs for pregnant and parenting teens, pregnancy prevention programs, and special substance abuse prevention counseling services. These programs isolate segments of young people according to a typology of risk factors. By their design they are more likely to work as intervention programs, not prevention strategies.

Those nations with comprehensive services and explicit sex education have lower rates of unintended pregnancy and abortion than the United States.

High school students are referred for special counseling and educational services if they are deemed to be at risk of substance abuse. By isolating subsets of youth, these programs fail, by definition, as prevention efforts. They reinforce the myth that risk taking and boundary testing are the exceptions rather than the rule of adolescent development, and they give credence to the notion that there are such things as “good” kids and “bad” kids. By denying the normalcy of risk taking among all adolescents and failing to develop strategies that recognize that normalcy, program efforts are compromised by the conflicted messages of their design.

This tendency to subdivide and isolate young people as a means of providing dedicated services is not confined to the educational community. The CDC provides HIV prevention funding for out-of-school youth who are considered to be high risk. This practice is often mirrored at the state and local level by funding conduits or funding agencies. The underlying philosophy of these programs implies a clear-cut distinction between the behavior of young people who are in school and the behavior of those who are not, suggesting that an out-of-school youth is more likely to engage in high-risk behavior than an in-school youth. While, in the aggregate, this hypothesis may be true, from the perspective of protecting individual adolescents, this premise is not only false but counterproductive.

The tendency to take risks is associated with a stage of development. Though that tendency may be exaggerated among certain young people at certain moments, the greatest benefit will derive to adolescents when strategies are developed that are responsive to their stage of development. To the extent that resources are limited and allocated according to a priority that triages based on need, agencies that claim to serve high-risk out-of-school youth have a significant advantage over school-based programs in garnering public funding for HIV/AIDS prevention. There are, however, several problems with this approach to HIV/AIDS prevention for adolescents.

Youth in and out of School

Virtually all out-of-school youth were once in school, which means that school-based programs still provide the best means to reach the greatest number of young people. Three principles should guide HIV prevention strategies:

1. The earlier information about transmission and prevention is provided, the better.

2. The term out-of-school youth is a misnomer because these young people are more accurately “in and out of school,” attending school irregularly rather than not attending at all. This means that school-based prevention education programs must be offered at every grade level, on a regular basis. The programs must
include community-based components that are closely linked with the school, using outside advisors and presentations, as well as on-site referral and counseling services.

3. The competition for resources between school-based and community-based programs only contributes to the false notion that adolescent risk taking is an aberration which occurs among certain kinds of adolescents. HIV/AIDS prevention education should occur both inside and outside schools.

A strong argument can and should be made for providing a base funding level for school-based HIV/AIDS prevention education and using these programs as the foundation upon which supplementary and community-based programs and services can be built.

The Responsibility for HIV/AIDS Education: Public Health System Versus Education System

The Cost of Concessions

Historically, professional health providers and educators have made concessions, succumbed to public pressure, on issues related to adolescent health. These compromises have been made to mitigate controversy and appease those who either for religious or personal reasons are more comfortable with a romanticized version of adolescence than with a realistic one.

In dealing with sex education, many people in education were able to tolerate a watered-down curriculum and a parent’s right to remove their child from certain classroom discussions. Such concessions were justified by the conclusion that potential gains outweighed losses. Schools would teach human sexuality, and that was progress in addressing adolescent pregnancy. With school-based health clinics, many people in the health profession accepted parental consent requirements that confined health services to those young people whose parents agreed. The result was the confining of school-based health services to a subset of students in a small proportion of schools where politics and resources permitted. The tendency of adolescents to experiment coupled with the prevalence of the HIV virus makes it harder to take comfort in such compromise.

In considering the need for expanded and explicit HIV/AIDS education in schools, there are some who take the position that the controversy provoked by this subject jeopardizes the consensus required to provide effective public education. They argue that the greater good

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is served by maintaining the balance of support for education from a cross section of the community, including those opposed to HIV/AIDS education, even if it means watering down the HIV/AIDS program or compromising on program components. These people describe HIV/AIDS as strictly a public health issue that should be managed by the public health community. They further argue that, given the enormity of the task of educating the nation’s young, it is neither necessary nor wise to expand the reach of schools into this realm.

In reality, there is a long history in this country of providing noneducational services to students in public schools. Moreover, there is a history of using public schools as a vehicle for public health messages and public health services. The incorporation of HIV/AIDS education into a school’s comprehensive school health agenda is no different, in this way, from turn-of-the-century efforts to assimilate new immigrant children to the proper use of a toothbrush. What makes this issue different, however, is its relationship to adolescent development, adolescent risk behavior, and adolescent sexuality. If HIV infection were transmitted through water fountains, it is hard to imagine a world in which battles would be fought over curriculum content dealing with modes of transmission and prevention.

For public policymakers, it is critical to understand that compromises on HIV/AIDS prevention have a price and that the opposition one seeks to assuage by concession is rooted in beliefs deeper and with greater implications than HIV prevention education alone. This is not to say that compromise has no place in HIV/AIDS prevention education, but
rather to caution those in positions of power that the cost of some compromises may be measured in program effectiveness. The effectiveness of prevention education strategies will be measured in lives that are saved or lost.

In New York State, education department regulations require that local boards of education establish HIV/AIDS Advisory Councils to advise on the content and design of HIV/AIDS prevention education programs. To allay the potential for controversy associated with the development of such programs, the state mandated that

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the advisory councils include representatives from the religious sector. The reserved role for religion is in stark contrast to the lack of a mandate concerning the participation of HIV/AIDS experts. While the requirement may pacify some religious interests, it does not necessarily contribute to the quality of HIV/AIDS education, whereas a requirement that HIV/AIDS experts be involved would indeed contribute to the quality of the program developed.

Efforts to address adolescent health and sexuality by adolescent health advocates and public servants inevitably collide with some religious precepts of certain groups, as well as with some parents who deny the risks their children face. Adolescent health issues and HIV/AIDS prevention education raise challenging and complicated social and political questions about the balance of church and state interests, their constitutionally established separation, parents’ roles, and children’s rights.

Compromise is not necessarily anathema to high-quality HIV/AIDS prevention, but concessions should be made carefully to protect against a tradeoff that lacks substantive merit. HIV/AIDS prevention programs should stay true to the medical realities and the realities of the adolescent experience. Controversy avoidance alone is not a goal of effective HIV/AIDS prevention.

Condom Availability as an HIV/AIDS Prevention Strategy

Who Wants Condoms in Schools?

In May and June of 1992, Louis Harris and Associates conducted a survey of 300 public school districts and found that 8% of all public middle and high school students now attend schools in districts where condom availability programs have been approved.22 More significant was the finding that 34% of the nation’s middle and senior high school students attend schools where substantial discussion has occurred about HIV/AIDS education and the merits of expanding HIV/AIDS education programs. Public debate about the quality of existing HIV/AIDS prevention education and the potential for new or expanded program efforts provide communities with an opportunity to review the health status of young people and incorporate adolescent risk behavior into the discussion of appropriate educational and health-related programs and services.

As of the fall of 1992, at least 15 and as many as 50 school-based health centers were making condoms available to sexually active students as a strategy for preventing pregnancy and the spread of sexually transmitted diseases and HIV.23 Eleven school-based condom availability programs were being implemented at that time, and another 10 programs were being developed.

Where Are Condoms Available in Schools?

While such school districts as Los Angeles, San Francisco, Philadelphia, and Washington, D.C., have all approved condom availability policies, condom availability is not a strategy confined to large city school districts (see Table 1). Commerce City, Colorado, has adopted a policy, as have Falmouth and Martha’s Vineyard, Massachusetts. The appropriateness of condom availability as a prevention strategy for adolescents can be determined only on a community-by-community basis. Communities must discuss their own HIV/AIDS prevention strategies in the context of local health statistics and an assessment of risk behavior among local youth.
Table 1

Cities with Schools Offering Condom Availability Programs Identified as of June 1, 1994

<table>
<thead>
<tr>
<th>School-Based Health Center Programs Implemented</th>
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<tr>
<td>Nationally, Advocates for Youth estimates that more than 70 school-based health clinics make condoms available to sexually active students, including those in Baltimore (MD), Boston (MA), Cambridge (MA), Chicago (IL), Culver City (CA), Dallas (TX), Little Rock (AR), Los Angeles (CA), Miami (FL), Minneapolis (MN), New York City (NY), Philadelphia (PA), Portland (OR), Portsmouth (NH), Quincy (FL), Readfield (ME).</td>
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<th>Schoolwide or Districtwide Programs Approved</th>
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<tr>
<td>Alexandria (VA), Amherst (MA), Bedford (MA), Brookline (MA), Cape Cod Vocational (MA), Chapel Hill (NC), Chelsea (MA), Commerce City (CO), Falmouth (MA), Franklin County Vocational (MA), Harvard (MA), Holden (MA), Lexington (MA), Lincoln/Sudbury (MA), Los Angeles (CA), Martha’s Vineyard (MA), Mohawk Trail, Regional (MA), Moretown (VT), Mt. Desert (ME), Mt. Greylock, Regional (MA), New Haven (CT), New York City (NY), Newton (MA), North Shore, Regional (MA), Northhampton (MA), Philadelphia (PA), Provincetown (MA), Ralph C. Mahar, Regional (MA), San Francisco (CA), Santa Fe (NM), Santa Monica (CA), Seattle (WA), Sharon (MA), Somerville (MA), Stockton (CA), Wachusett (MA), Washington (DC).</td>
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<th>Proposals Defeated</th>
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<tr>
<td>Albuquerque (NM), Chester (VT), East Lyme (CT), Kennbunkport (ME), Lake Washington (WA), Millville (NJ), Nashua (NH), San Lorenzo Valley (CA), Talbot County (MD), Tamalpais HS (CA), Teaneck (NJ).</td>
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\(^{a}\)Formerly Center for Population Options.  
\(^{b}\)The Massachusetts Department of Education recommends that all schools in the state consider school condom availability as part of comprehensive HIV education. As of June 1, 1994, some 42 school committees had voted against condom availability.

HIV/AIDS prevention education generally, and condom availability specifically, were the focus of considerable attention when, in February of 1991, the New York City Board of Education, the largest school district in the nation, adopted a policy of condom availability in high schools. The program design resulted from a collaborative effort between the school system and the public health department and other private and public experts on adolescent development and HIV transmission. The program relied substantially on the involvement of the health and adolescent advocacy community, as well as parents, faculty members, and students. See Box 1.

The New York City program, which was implemented in November 1991, affects the lives of more than 275,000 high school students in the New York City schools. By involving parents and students as partners with school faculty members in the process, the program has nurtured trust among all members of the school commu-
The New York City condom availability program includes the following provisions, many of which are unique to the New York program design and have not been adopted by other school districts around the country:

**Input**
Copies of the draft program design were circulated to more than 1,000 organizations and individuals, including parent groups, concerned about education issues generally and HIV/AIDS education specifically.

**Involvement**
The program design involves parents, students, and faculty members, as well as outside experts on HIV/AIDS, as members of school-based HIV/AIDS education teams.

**Confidentiality**
The program establishes school-based condom availability for all high school students without parental consent or the right of parents to opt children out of the program. This provision protects the anonymity of the young people who wish to participate. The program is strictly voluntary; no student is required to take a condom.

**Training**
HIV/AIDS education teams—including students, parents, and school faculty members—enroll in a three-and-one-half day training program designed and delivered by experts from a range of local and national public and private health and HIV/AIDS organizations.

**School Plan**
HIV/AIDS education teams are given latitude in the design of school-specific strategies, within guidelines established by the central school district.

**Quality**
Schools whose program design fails to meet the minimum standards promulgated by the chancellor’s office are given technical assistance by a team of HIV/AIDS and adolescent behavior experts.

** Volunteers**
Only teachers who volunteer hand out condoms to high school students. They are team members and are fully trained prior to making condoms available.

**Readiness**
Schools are not permitted to make condoms available until the school-based HIV/AIDS education team leader and the school principal agree that the school is ready, they have completed their training, and they have had their classroom instruction observed and approved by an independent educational administrator.

**Partnership**
The program is a model of public-private partnership, with the private sector contributing condoms as well as staff to assist with school-based implementation and the public sector reallocating health education resources to maximize support for HIV/AIDS prevention efforts.

### Evaluation of the Plan

By the time the Board of Education approved the plan to expand HIV/AIDS education with condom availability in 1992, the New York City school system’s Office of Research, Evaluation and Assessment (OREA) was organizing a process evaluation. Shortly after the plan was approved, several meetings were held with outside organizations, mostly from academic research institutions, who were interested in evaluating the plan from different perspectives. Four research organizations combined forces to study the high school HIV/AIDS prevention education program, in particular, the impact of condom availability on adolescent knowledge and behavior.

This consortium, including the Academy for Educational Development (a nonprofit organization with more than 10 years of experience helping schools implement and evaluate educational reform), the Hunter College Center on AIDS, Drugs and Community Health, the Health Studies Department of New York University, and the National Center for Health Education, will use the Chicago school system, which has not adopted condom availability, as a comparative city. In this way, the evaluators hope to isolate the effect of specific program components used in New York City high schools. While the evaluation is under way, as of this writing, they have not published their findings. They are focusing on the following issues and questions:

- Does a school-based HIV/AIDS education program which includes a voluntary condom availability component lead to sexual and drug behavior change among students?
- Does the program lead to changes in communication about sexuality, drugs, AIDS, and condoms among students, sexual partners, teachers, parents, and other adults?
- Does the program contribute to changes in the school's social environment and normative attitudes regarding AIDS, drugs, sexuality, and condoms?
- Do different levels of program intensity lead to different outcomes in risk behavior, communications, or school environment?
- Does the program have different impacts on different groups?
- Does the program have different impacts in different settings (types of school)?
- How does political, administrative, parental, community or faculty opinion influence program implementation?
- Does the program serve as a “wedge” for students to raise other concerns about health and sexuality in the school?

The internal evaluation, conducted by OREA, has been ongoing since the program’s inception in February of 1991. The first report, titled *OREA Report: Evaluation of the HIV/AIDS Education Program/Including Condom Availability 1990-92*, was issued in the fall of 1993. Overall, the program was found to have “substantial accomplishments” with respect to improving the quality of school-based HIV/AIDS education in New York City’s high schools.
The goals of OREA’s evaluation were to

- document and assess the program’s training and resource development process;
- provide feedback to program planners and schools on implementation and program barriers;
- determine the program’s impact on students, teachers, and school staff;
- identify strategies associated with positive program outcomes; and,
- recommend changes for strengthening the program.

OREA evaluators examined the goals of the chancellor’s expanded HIV/AIDS program and the progress made by schools in meeting those goals. The program required the formation of HIV/AIDS education teams in all high schools. Each team, including, at a minimum, parents, students, and faculty members, was required to participate in a training program and was responsible for ensuring the provision of a minimum of six classroom lessons per grade on HIV/AIDS prevention. In addition, the teams were responsible for designing a school-specific strategy for making condoms available.

The teams were to recruit faculty volunteers as health resource room staff to make condoms available. The chancellor’s program encouraged the involvement of community-based organizations in the development and implementation of HIV/AIDS prevention education efforts. Finally, the program included a peer education component, funded entirely with private dollars. OREA’s evaluation examined each of these components, the degree to which they were implemented as they were designed, and the impact on student and staff awareness and behavior.

Using a 10-high-school sample, the OREA evaluators found that all of the schools had established HIV/AIDS education teams which were broadly representative of the school community. The teams ranged in size from 10 to 40 members. All of the school principals rated the overall functioning of the team as “excellent.” And, in general, team members expressed enthusiasm about their involvement in the program as well.

The training program was equally well received, according to the evaluators. Seventy-seven percent of those people interviewed about the training described their experience as either “very useful” or “somewhat useful.”

On the curriculum issue, the findings were more uneven. Evaluators found that school staff relied on a variety of sources for the HIV/AIDS education because the Board of Education had not adopted a high school level curriculum on HIV/AIDS prevention education. At the time of this writing, the Board of Education’s HIV/AIDS Advisory Council is still reviewing a curriculum for grades 7 through 9. This curriculum has been under review for more than two years. The delays associated with the development and release of curricula for use in schools are due in large part to the Board of Education’s internal conflicts over the explicitness of the language used and the emphasis on protection against transmission versus abstinence education.

Condom availability was found to have been implemented without incident in each of the sample schools, with four principals reporting having been “pleasantly surprised” by the maturity and seriousness with which the students accepted condom availability. Principals reported minimal parent opposition and stated that one obstacle they faced in program implementation was lack of space for health resource rooms in overcrowded schools. OREA evaluators found that most students thought the HIV/AIDS education program was having a positive impact in three areas: increasing the likelihood that students would get HIV counseling or testing; opening up communication between students and staff with respect to student health concerns; and increasing the use of condoms among sexually active students. Students who were members of the HIV/AIDS education teams thought that the program had a more positive impact than did students who were not team members.

Two-thirds of the health resource staff were women. The number of volunteers for each school ranged from three to 30. Of the 10 schools visited, only two had a single health resource room dedicated exclusively for the dissemination of health information and condoms. Staff and students reported that a single site meant that people knew it as a “condom room,” making some students less likely to use it.

The evaluators indicated that their own impression, over the course of their site visits, was that, on the topics of HIV/AIDS and sexuality, the “lines of communication had opened significantly between student and program staff.” One team leader stated that the program provided an opportunity for students to talk about sexuality and drug abuse issues. Another said the program gave students coming from homes with HIV-positive family members someone with whom to talk about their concerns and feelings. One staff member described the condoms as a “carrot” used to engage students in broader discussions.

Nine of the 10 schools relied on the involvement of community-based organizations in the implementation of their programs. Most were either HIV/AIDS specific agencies or public health and social service organizations.

A more complete assessment of the effectiveness of the peer education program is under way, though the evaluators found general support for this component as well, with positive responses from both students and faculty involved.

OREA’s evaluation demonstrates that the New York City public high schools have made progress in implementing key provisions of the program. Each of the 10 sample schools met the minimum requirements for forming HIV/AIDS education teams, staffing and stocking health resource rooms, teaching six lessons at each grade level, and conducting parent information sessions. Implementation of condom availability was found to have gone very smoothly with reports that both student and staff displayed mutual respect in the process. Team leaders were asked their opinions about the impact of the chancellor’s expanded HIV/AIDS education program including condom availability. Their answers addressed the impact of the entire program, rather than specific components. Overall, they indicated that the program had a positive impact in the areas of heightened awareness, increased openness, and better communication and mutual respect.

The basic challenge is to enable health care professionals and educators to work together to provide comprehensive services with categorical funding streams.

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tenity and has given parents and students a genuine role in the implementation of a critical program effort. In addition, with parents and young people working side by side, each has the opportunity to better understand the other’s perspective and experience. The training program for the school-based HIV/AIDS education teams emphasizes the importance of opening lines of communication, encouraging discussions of issues that have traditionally been too controversial and taboo for the average classroom.

In the summer of 1991, New York City Schools Chancellor Joseph Fernandez extended an invitation to more than 35 research institutions from across the nation, inviting them to evaluate the program’s effectiveness. Eight different institutions came forward with evaluation plans. Four institutions formed a consortium to focus specifically on the high school HIV/AIDS prevention program, with a special emphasis on the impact of condom availability on adolescent attitudes and behavior. These organizations raised their own financial support to undertake their studies. They participate in a study group designed to keep lines of communication open between and among all researchers. This group is convened by staff from the Board of Education’s Office of Research, Evaluation and Assessment (OREA). The willingness of the school system to cooperate with this level of external assessment activity was unprecedented and again reflected the school system’s effort to collaborate across disciplines and institutional lines to ensure high-quality HIV/AIDS prevention strategies. In addition to the external evaluations, the school system implemented a process evaluation, documenting the program’s progress in meeting its goals.

Two types of evaluations have been conducted of the New York City Board of Education experiment: an internal evaluation by the school system’s OREA and an external evaluation by teams in surrounding institutions and academic research centers. Often school systems are reluctant to have outside evaluators working within the schools. In this instance, the Chancellor welcomed the scrutiny of the independent research community as an important means of learning from this bold social experiment. In fact, meetings were held to permit researchers to exchange ideas and approaches to facilitate a series of studies using different perspectives and study designs, rather than a single outcome study. Details of both the internal and external evaluations are presented with the description of the New York City program in Box 1.

The New York City program caught the interest of the media and the public nationally and internationally. By braving the controversy of condom availability as a proposed strategy to prevent the further spread of HIV/AIDS among adolescents, the New York City school system enabled other educational leaders to consider the issue and explore program options. By the time the New York City Board of Education approved condom availability, journalists everywhere were asking local school boards about the state of HIV/AIDS prevention and their views on condom availability. These inquiries placed considerable pressure on school boards large and small to assess their own HIV/AIDS prevention efforts and improve or refine their program strategies.

Resources Available for Educational Programs

While some states and localities make small contributions to HIV/AIDS education, the bulk of the funding comes from the CDC. According to the National Association of State Boards of Education, in 1994 Congress appropriated a total of $48 million for HIV/AIDS prevention for school and college-aged youth combined. The Associate Director of the Office of HIV/AIDS Prevention at the CDC reports that most of these funds are used for school-based HIV/AIDS prevention programs. The allotment, on its own, is wholly insufficient to provide adequate school-based HIV/AIDS prevention education. Even if the entire allocation were dedicated to the New York City Public School system, it would represent slightly more than $48 per student, or $1,680 per class. In fact, in 1991-92, the New York City public schools, with nearly one million children enrolled, received approximately
$500,000 from the CDC for school-based HIV/AIDS prevention education.

**Conclusion**

The policy recommendations that follow underscore the need for collaboration across disciplines and institutions, and coordination of resources to develop effective adolescent HIV/AIDS prevention programs. The basic challenge is to enable health care professionals and educators to work together to provide comprehensive services with categorical funding streams. As a result of the disaggregation of resources, programs have compartmentalized young people and their needs. The unintended outcome of categorical funding has been to separate those young people who most need integration into the larger system and isolate services that would be best delivered comprehensively. The result of this categorical approach is the proliferation of disease-specific programs working in isolation and often total ignorance of each other’s activities. Hence, there are school systems developing AIDS curricula separate from the health care community, community-based dropout prevention programs functioning in total isolation from school systems, and even school-based substance abuse prevention programs developed in isolation from AIDS prevention programs. In these instances, service systems are defined narrowly, and opportunities to share resources and improve the quality of services are lost.

The integrated approach to comprehensive service systems that we propose specifically for adolescent AIDS prevention will challenge our traditional isolationist approach to both health care and education. Where health professionals come into schools to provide medical services, they should be involved in curriculum development, staff training, and community education projects. Where educators have been working by themselves developing health education curriculum and training teachers, health care professionals should be assisting them in the future.

Until we develop strong systems at the federal and state levels to support the coordination of resources for the purpose of promoting and providing accurate information about this epidemic and means to prevent its spread, the handful of fledgling programs that have been launched in communities around the nation are fighting an uphill battle against a collective denial of the reality of adolescent sexuality and risk behavior. As professionals and policymakers, we must set our sights on dispelling the myths and clarifying the truths about HIV transmission and the best means of prevention, and on tackling the taboos that, in the age of AIDS, threaten our young peoples’ lives.

**Specific Policy Recommendations**

The recommendations that follow focus on specific steps to be taken at all three levels of government—federal, state, and local—to help the nation’s youth successfully acquire the knowledge, skills, and services needed to grow up in the midst of a world pandemic. In some instances, the proposals are meant to initiate and, in other instances, further cultivate partnerships between health and education to strengthen the respective efforts of each. The recommendations should be implemented simultaneously and quickly in view of the rapid spread of the epidemic.

**Recommendation 1**

The Department of Health and Human Services (DHHS) should be authorized, through its new Office of Adolescent Health, to coordinate personnel and resources for HIV prevention and services for youth within DHHS, as well as between DHHS and the federal Departments of Education (DOE), Defense (DOD), and Labor (DOL). See Figure 1.

**Rationale**

The Preventive Health Amendments of 1992 provide specific guidance to establish a new Office of Adolescent Health under Title XVII of the Public Health Services Act. The duties of this office would include

- coordinating within DHHS all activities related to disease prevention, health promotion, preventive health services, health information and education;
coordinating similar activities in the private sector;
- giving grants for demonstration projects to improve adolescent health (including training of health care workers and educators);
- establishing and maintaining a National Information Clearinghouse on Adolescent Health; and,
- developing a national plan for improving adolescent health care and health education.

Responsibilities
The following are examples of HIV-specific responsibilities for this office:
- collation and review of recommendations of the six key reports on adolescent health and HIV;\textsuperscript{25-30}
- interdepartment and program communication within DHHS about existing and proposed programs, including key Public Health Service agencies such as, CDC’s Division of Adolescent and School Health, Division of HIV/AIDS, Health Promotion/Disease Prevention, STD Prevention, the National Institutes of Health (particularly NICHD, National Cancer Institute, National Institute of Allergy and Infectious Diseases), the Agency for Health Care Policy and Research, the Food and Drug Administration, Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, Office of Assistant Secretary of Health, National AIDS Program Office, National Vaccine Program Office, Office of Disease Prevention and Health Promotion, Office of Population Affairs, Office of the Surgeon General, Office of Women’s Health, and the President’s Council on Physical Fitness;
- analysis of funded HIV prevention and research programs to determine both the actual number of adolescents served or participating in programs, and the amount of money and resources dedicated to adolescents exclusively;\textsuperscript{31}
- review of current policies regarding HIV prevention counseling and HIV testing and services in other federal departments,
including current policies of mandatory HIV testing as an admission criterion for programs within DOL (Job Corps, Peace Corps programs, and others geared to young people), and DOD (programs affecting adolescents under the age of 24 in all branches of the military), and also a review of existing programs within DOE that address adolescent health, HIV/AIDS prevention, and substance abuse prevention (Office of Comprehensive School Health, Middle School Education, Drug Free Schools); and,

- review of funded research and service projects within NIH, HRSA, and CDC to ascertain the number of adolescents included, not just the age bracket for inclusion, and the amount of and percentage of research funds specifically aimed at HIV prevention, evaluation, and care of HIV-infected adolescents.

**Recommendation 2**

A network of State Offices of Adolescent HIV/AIDS Prevention should be established to maximize coordination of resources across health and education, and support the development of high-quality interdisciplinary approaches for both school- and community-based adolescent HIV/AIDS prevention programs. See Figure 2.

**Rationale**

The federal government should make funding available to the executive branch of state governments to support the establishment of an Office of Adolescent HIV/AIDS Prevention. In addition to facilitating adolescent HIV/AIDS prevention efforts within the state, these offices would serve as a national network for the federal government to disseminate infor-
It is of particular importance that guidelines be based on empirical data, studies of adolescent and child development, and health status data.

...
quality HIV/AIDS education at all grade levels and should establish and enforce minimum program quality standards in its delivery. See Figure 2.

**Rationale**

To qualify for this funding allocation, schools should be required to provide HIV/AIDS education at all grade levels, K-12, to provide staff development on HIV/AIDS, and to involve parents, as well as health and HIV/AIDS experts, in the development and regular review of curriculum and educational materials.

While currently every state either requires or recommends HIV/AIDS education, little is done to ensure that this education is provided, and even less is done to ensure program quality.

**Responsibilities**

The following are examples of responsibilities recommended to be fulfilled by school districts receiving per-capita funding allocations specifically for HIV/AIDS prevention education:
- meet minimum learner outcome standards for HIV/AIDS education by grade level;
- document annual review process for educational materials designed to keep the curriculum and supplementary educational materials up to date and consistent with current medical knowledge;
- demonstrate ongoing staff and parent education programs, with evaluations to ensure high quality and effective delivery;
- establish formal mechanisms to link prevention efforts with services, such as adolescent counseling and HIV testing services, care for HIV infected youth; and
- implement an evaluation, monitoring, and technical assistance system to facilitate school-based implementation of program efforts.

While curriculum and program guidelines should be promulgated at the state level, school districts should be given latitude in determining specific program strategies, and they should be encouraged to provide HIV/AIDS education as a part of a comprehensive school health education program. In this way, the per-capita funding allocation should not be restricted to a specific set of program activities, but rather, it should be linked to the accomplishment of broad-based goals, providing districts with the flexibility they need to allocate or redistribute resources to achieve those goals. For example, one goal of the per-capita funding allocation should be to foster stronger linkages with community-based health organizations. If a district has a plan for achieving this goal and would like to spend the resources on another aspect of the HIV/AIDS prevention effort, such as a peer education program, this should be permitted within the guidelines established by the state.

**Recommendation 4**

State education departments should establish a Health/Education Collaborative, a committee including health and education experts, to coordinate across disciplines and to advise on the development of adolescent HIV/AIDS prevention education program development. See Figure 2.

**Rationale**

A Health/Education Collaborative would establish a formal linkage between the health and education sectors at the state level and would be dedicated to ensuring high-quality HIV/AIDS prevention education through communication and the coordination of resources.

Unlike the proposed state Office of Adolescent HIV/AIDS Prevention, the collaborative would be comprised of health and education professionals who volunteer to participate and who are dedicated to coordinating existing resources within their own professional sector to ensure high-quality program efforts. Members of the collaborative would work closely with the Office of Adolescent HIV/AIDS Prevention, serving as advisors to that office and links to institutional resources.

**While currently every state either requires or recommends HIV/AIDS education, little is done to ensure that this education is provided, and even less is done to ensure program quality.**

Membership on the collaborative should be solicited from the professional health and education communities, as well as from the public departments of health and education. The collaborative would require minimal staff support and would report to the Commissioners of Health and Education.
Responsibilities
The following are examples of specific responsibilities for the collaborative:

- inventory resources—including data collection capability, service delivery systems, and financial support—within the institutions represented on the collaborative;
- propose resource sharing opportunities to support program development for adolescents;
- participate in the review of HIV/AIDS educational materials, including endorsements of materials considered to be of high quality;
- publish a newsletter featuring model collaborations between health and education;
- foster maximum cooperation across the disciplines of health and education; and,
- cultivate regional capability for health care workers to collaborate with education experts in addressing adolescent-specific HIV referral, counseling, testing, and treatment issues.

Recommendation 5
School systems should establish a health and education HIV/AIDS advisory committee that includes educational administrators as well as representatives from the public and private health care community. See Figure 3.

Rationale
School boards and school administrators should tackle complicated and controversial issues as they review and improve their HIV/AIDS prevention education programs. The public and private health care professionals should assist the school district to develop curriculum, program, and services strategies by reviewing health data, undertaking risk-behavior studies, and conducting a local health needs assessment. This assistance would ensure that the programs and strategies proposed for classroom instruction and school-based services are appropriate to meet the needs of the students.

Reporting to the school district superintendent, this advisory committee should consist of educational administrators and public and private health professionals who have volunteered to participate.

In addition to the benefits derived to the school district, the health community will gain from the experience as well by learning how schools address health-related issues, the range of services and resources available through the schools, and the process by which faculty are trained to teach health-related issues. Finally the health care community will gain insight into how best to use the education system to advance the public’s understanding of critical public health issues and concerns.

Responsibilities
The following are examples of specific responsibilities of the proposed health/education HIV/AIDS advisory committee:

- review adolescent health data, in particular data related to HIV risk behaviors;
- convene community education programs on HIV/AIDS issues and concerns for parents and other interested citizens to discuss health statistics, adolescent risk behavior, and model program strategies;
- review health education and, where available, HIV/AIDS education materials to assess the accuracy and appropriateness of the ways in which methods for HIV/AIDS prevention are presented and discussed;
- collect and disseminate information about model programs;
- develop a resource list of health care providers, including medical schools, counseling, HIV testing, and treatment services for adolescents, to be used by schools in the development of school-based plans for expanding HIV/AIDS prevention education;
- advise on the development of evaluation instruments to assess program effectiveness; and
- propose guidelines for content and age-appropriateness of topics to enable school-based review of supplementary educational materials, such as brochures, posters, videos, and the like.

Recommendation 6
High schools should establish HIV/AIDS education teams that include parents, students, faculty members, and community experts in health, HIV/AIDS, and adolescent development. See Figure 3.

Rationale
To ensure high-quality program strategies, high schools should be required to establish HIV/AIDS education teams with mandated participation from the school principal, along with parents, students, school staff, and outside health
experts. Program quality benefits from the involvement of parents, faculty members, and students in the design and development of school-based strategies for HIV/AIDS prevention. Programs are more likely to be well received and understood by the community as a whole when the whole community has been involved in their development.

While central school districts are in an ideal position to collect and disseminate information about HIV/AIDS issues and to assist schools in identifying model programs, the school community itself is best suited to select specific strategies to effect a particular goal or objective. School-based HIV/AIDS education teams give parents, students, and faculty members a sense of program ownership, which helps sustain the school’s commitment to a program over time.

**Responsibilities**

The following are examples of responsibilities of high school-based HIV/AIDS education teams:

- review existing HIV/AIDS educational program within the school;
- develop a plan for expanding school community awareness of HIV prevention and improving school-based HIV/AIDS prevention education;
- review resource materials proposed for use in the school as part of the HIV/AIDS educational program;
- create a calendar of HIV/AIDS educational activities for the school year, including assemblies with outside HIV/AIDS experts, presentations by People Living With AIDS (PLWAs), and so on;
- develop a school-based assessment process by which the team can measure the effectiveness of its strategies;
- identify and publicize on-site counseling resources for students; and,
- establish a referral process to outside agencies that provide adolescent counseling services, as well as HIV testing, bereavement counseling, and HIV treatment programs.


