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AIDS Prevention and Education

Reframing the Message

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November 1989

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Introduction

In developing its agenda, the Citizens Commission on AIDS for New York City and Northern New Jersey has placed a high priority on education and prevention. In its "Ten Principles for the Workplace," the Commission emphasized the importance of the workplace as a site for AIDS education. In its appeal for expanded and equitably sited drug treatment facilities to break the link between AIDS and drug use, the Commission stressed access to appropriate and ongoing education for drug users and their partners. In its analysis of the health care crisis, the Commission called for increased resources to provide early intervention in HIV disease and to develop supportive services, including education and counseling, for those at highest risk.

This report addresses the issue of AIDS education and prevention directly. Its primary purpose is to refocus the public's waning attention on education as the primary mechanism for preventing HIV transmission. "Ten Myths about AIDS Education," included in this report, substitutes facts and sound policy recommendations for the prevalent misconceptions that hinder AIDS education. The main sections of the report synthesize the current research and experience in AIDS education and serve as a background for a series of recommendations to various public and private sectors of our varied communities. Wise investment in well-designed education programs has a double reward: lives saved and health care dollars conserved.

Finally, the report profiles a number of ongoing programs in New York City and New Jersey to show how creatively many people are tackling the challenge. These individuals and groups are only a sampling of the much larger community of AIDS educators working in diverse ways to convey information, attitudes, and skills that are essential to prevent HIV from making further inroads in our region.

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November 1989

Ten Myths About AIDS Education

Myth No. 1: Continued AIDS public education is not necessary because everyone already knows how HIV is and is not transmitted.

FACT: Although the level of knowledge has increased, large numbers of people still believe that they can catch AIDS from drinking glasses, toilet seats, and casual contact.

RECOMMENDATION: Public education about AIDS must remain a continuing priority.

Myth No. 2: Public service announcements have saturated the media with AIDS information.

FACT: Most AIDS campaigns conducted through public service announcements have had limited impact because they have been aired infrequently and erratically.

RECOMMENDATION: AIDS education campaigns should be aired during prime time and with the same exposure as commercial campaigns.

Myth No. 3: AIDS education for heterosexuals is not necessary because AIDS is not spreading beyond the gay or drug-using communities.

FACT: AIDS is spread through heterosexual as well as homosexual sex. The percentage of women who do not use drugs and are being infected heterosexually is increasing, as is the percentage of adolescents of both sexes.

RECOMMENDATION: Education and prevention programs should be aimed at heterosexuals, especially teenagers and drug users, in addition to gay and bisexual men.

Myth No. 4: AIDS education in schools is difficult to introduce because so many parents object.

FACT: All public opinion surveys show that the vast majority of parents support some form of AIDS (and sex) education in schools. The precise content of the education is more controversial.

RECOMMENDATION: All public and private schools should provide AIDS education from grades K-12, and should educate parents about the curriculum as well as about ways to discuss AIDS with their children. AIDS educators should meet with parents who object, to explain the curriculum and reduce fears.

Myth No. 5: If AIDS instruction is provided in the schools, adolescents do not need any additional education.

FACT: Even with the best curriculum and the most highly skilled teachers, AIDS education that is limited to the classroom cannot have the same impact as AIDS education that is repeated in many different settings outside the classroom.

RECOMMENDATION: Community-based organizations should be supported by public and private funds in providing AIDS education to adolescents.

Myth No. 6: Continued AIDS education for gay men is not necessary because they have all adopted "safer sex" practices.

FACT: Although gay men in general have substantially reduced risky behavior, some have been unable or unwilling to do so and others have difficulty in maintaining behavior change over long periods.

RECOMMENDATION: Targeted, explicit education for gay men that provides motivation for sustained behavior change should be continued and supported by public agencies as well as community-based groups.

Myth No. 7: AIDS education for drug users is a waste of time and money because they are unconcerned about their health and unable to change their behavior.

FACT: Concerned about AIDS and increasingly aware of the risks, many drug users have stopped sharing needles or are sharing less frequently, but their sexual behavior has been slower to change.

RECOMMENDATION: Targeted AIDS education for drug users should be expanded and supported by public funds. Special emphasis should be placed on changing sexual behavior because drug users continue to be the main source for heterosexual transmission of HIV.

Myth No. 8: Continued AIDS education for blood donors is not necessary because everyone knows who should and should not donate blood.

FACT: Although the safety of the blood supply has dramatically increased since HIV antibody testing was introduced, two problems remain: (1) many people who are eligible to donate do not do so out of unfounded fear that they can contract AIDS in this way, and (2) some HIV-infected heterosexuals do not understand or acknowledge their risk and continue to donate blood.

RECOMMENDATION: Blood banks and those who organize workplace or community blood drives should develop more explicit information about behavioral risk, and easy, confidential ways for at-risk donors to exclude themselves.

Myth No. 9: If people are given accurate information, they will change their attitudes and behavior.

FACT: Knowledge alone does not lead to changes in attitude or behavior. Some people with high levels of knowledge continue to engage in risky behavior because they do not perceive themselves to be at risk. Some attitudes and behaviors are so deeply held that information alone will not change them.

RECOMMENDATION: Prevention programs should do more than provide information -- they should also give people skills and techniques to change attitudes and behavior.

Myth No. 10: Fear of death is the most effective motivator in changing behavior.

FACT: While a certain level of anxiety can heighten personal perceptions of risk, messages that stress fear alone are easily denied or screened out.

RECOMMENDATION: AIDS prevention messages should create a sense of personal risk, should emphasize the possibilities for protecting oneself and gaining control over the threat, and should reinforce the idea that AIDS is preventable. There is no advantage in creating a sense of inability to control the situation.

Diez Mitos Con Respecto a la Educación Acerca del SIDA

Mito Número 1: La continuación de la educación pública acerca del Sida no es necesaria porque todos ya sabemos como la infección VIH es y no es transmitida.

EN REALIDAD: Aunque el nivel de información ha aumentado, hay un gran número de individuos que todavia piensan que se puede contraer el SIDA a través de vasos, baños públicos, y contacto casual.

RECOMENDACIóN: La educación pública acerca del SIDA debe permanecer como una de nuestras grandes prioridades.

Mito Número 2: Anuncios para el servicio del público han saturado la radio, la televisión, y los periódicos con información acerca del SIDA.

EN REALIDAD: La mayoría de las campañas acerca del SIDA que se han desarollado a través de anuncios públicos han tenido un impacto limitado porque han sido transmitidas infrecuéntemente e irregularmente.

RECOMENDACIóN: Las campañas de educación acerca del SIDA deben ser transmitidas durante las horas principales del día y con la misma frecuencia y exposición que son transmitidos los anuncios comerciales.

Mito Número 3: La educación acerca del SIDA para los heterosexuales no es necesaria porque el SIDA no se está transmitiendo fuera de las comunidades gay o de las que usan la droga.

EN REALIDAD: El SIDA se transmite a través del sexo heterosexual y homosexual. El porcentaje de las mujeres que no usan la droga y que se han infectado por medio del sexo heterosexual está aumentando, tan bién como el porcentaje de adolescentes de ambos sexos.

RECOMENDACIóN: Programas para educar a la gente acerca del SIDA y prevenir la infección VIH deben dirigirse hacia las personas heterosexuales, especialmente hacia esos adolescentes e individuos que usan la droga, además de los hombres gay y bisexuales.

Mito Número 4: La educación acerca del SIDA es difícil de introducir porque hay muchos padres que no están de acuerdo con que sus niños reciban este tipo de educación.

EN REALIDAD: Todas las encuestas de la opinión pública indican que la mayoría de los padres apollan algún tipo de educación pública en las escuelas acerca del SIDA. El contenido preciso y particular de estos programas educacionales es mas contencioso.

RECOMENDACIÓN: Todas las escuelas públicas y privadas deben proveer educación acerca del SIDA desde kindergarten hasta el duodécimo grado. Las escuelas también deben educar a los padres con respecto al programa de estudios y a las maneras que ellos puedan utilisar para hablar acerca del SIDA con sus niños. Educadores profesionales que se especialisan en el campo del SIDA deben reunirse con los padres que rechasan este tipo de educación para explicarles el programa de estudios y reducir el temor que ellos puedan sentir.

Mito Número 5: Si la educación acerca del SIDA se provee en las escuelas, adolescentes no necesitan ningún otro tipo de educación adicional.

EN REALIDAD: Aun con el mejor programa de estudios y con maestros superiores, la educación acerca del SIDA que se limita al salón de clase no puede tener el mismo impacto que tiene la educación que pueda ser repetida en varios ambientes diferentes fuera del salón de clase.

RECOMENDACIÓN: Las organizaciones y agencias dentro de las comunidades locales deben ser apolladas por fondos públicos y privados para que puedan continuar educando a los adolescentes acerca del SIDA.

Mito Número 6: Continuar la educación acerca del SIDA para hombres gay no es necesario porque todos ellos han adoptado prácticas sexuales mas seguras o "safer sex."

EN REALIDAD: Aunque por lo general hombres gay han reducido los comportamientos de riesgo alto, algunos han sido incapaces o indispuestos a hacerlo y otros han tenido dificultad manteniendo el cambio de comportamiento a través de largos periódos de tiempo.

RECOMENDACIÓN: La educación particular y dirigida especialmente hacia la población de hombres gay que provee la motivación para sostener un cambio de comportamiento debe ser continuada y apollada por las agencias públicas y los grupos de la comunidad.

Mito Número 7: La educación acerca del SIDA para los que usan la droga es una pérdida de tiempo y dinero porque ellos no le dan ninguna importancia a la salud y son incapaces de cambiar su comportamiento.

EN REALIDAD: Preocupados por el SIDA y enterados de los riesgos, muchos individuos que usan la droga han parado de compartir las agujas o las comparten menos a menudo, pero el compartamiento sexual de estos ha cambiado muy léntamente.

RECOMENDACIóN: La educación particular y dirigida especialmente hacia los que usan la droga debe ser expandida y apollada por los fondos públicos. Debemos acentuar la necesidad de cambiar el comportamiento sexual porque los que usan la droga continuan siendo el vehículo principal en el cual se transmite heterosexualmente la infección VIH.

Mito Número 8: La educación acerca del SIDA para los que donan sangre no es necesaria porque todos saben quien debe y quien no debe donar sangre.

EN REALIDAD: Aunque la seguridad de la provisión de sangre ha aumentado dramaticamente desde que el examen para detectar la infección VIH fue introducido, dos problemas permanecen: (1) mucha gente que son eligibles para donar sangre no lo hacen por temor, sin base, de contraer el SIDA en está manera, y (2) algunos heterosexuales infectados con VIH no entienden o aceptan el riesgo y continuan a donar sangre.

RECOMENDACIóN: Bancos de sangre y esos individuos que organizan donaciones de sangre en el lugar de empleo o en la comunidad deben desarollar sistemas de información mas explícitos sobre los riesgos asociados con el comportamiento. Bancos de sangre y esos individuos que organizan donaciones de sangre también deben desarollar prácticas fáciles y confidenciales que permitan que los individuos de alto riesgo puedan excluirse ellos mismos.

Mito Número 9: Si la gente recibe información exacta, cambiarán las actitudes y el comportamiento.

EN REALIDAD: El conocimiento solo no puede cambiar la actitud o el comportamiento del individuo. Algunas personas con alto nivel de conocimiento continuan comportandose en una manera peligrosa porque no piensan que se están arriesgando.

RECOMENDACIóN: Programas de prevención deben hacer mas que simplemente proveer información -- deben también ofrecerle a la gente la habilidad y la técnica para que puedan cambiar la actitud y el comportamiento.

Mito Número 10: El temor de la muerte es la motivación mas fuerte para el cambio del comportamiento.

EN REALIDAD: Mientras que cierto nivel de ansiedad puede permitir que el individuo se perciba en peligro, mensajes que acentuan solo el temor son fácilmente negados o rechasados.

RECOMMENDACIóN: Mensajes de prevención con respecto al SIDA deben crear un sentido de riesgo personal en el individuo; deben acentuar las posibilidades que existen para protegerse contra está infección y para controlar está amenaza; y deben también reforzar la idea que el SIDA es evitable. No hay ninguna ventaja en el hecho de crear un sentido de incapacidad o inabilidad de controlar la situación.

AIDS Prevention and Education: Reframing the Message

Near the close of the first decade of the AIDS epidemic, there are signs of progress. For the first time, people infected with the Human Immunodeficiency Virus (HIV) can be given a message of hope: new drugs and treatments offer the potential to prolong life and to improve its quality, although no cure or vaccine is on the horizon. But the hopeful news must not obscure the primary goal of preventing HIV infection.* And here the record is mixed.

The American public's knowledge about modes of transmission has steadily increased, although myths and misunderstandings about specific facts continue. Largely through their own intensive efforts, organized gay communities have fostered the most extensive health-related behavior change in the shortest time in recent history; nevertheless, some gay men continue to engage in risky behavior. Also some intravenous drug users have modified their needle-sharing behavior, although not their sexual behavior to the same degree.

While still a small percentage of the total, women and adolescents represent the fastest-growing category of new HIV infections, and education efforts targeted toward these groups have thus far made little headway. Education has largely failed to address the needs of hidden populations such as bisexual men, men of color who have sex with other men but do not identify themselves as gay, homeless youth, school dropouts, and people with mental or physical disabilities.

Despite many excellent and innovative programs, some of which will be described in this report, prevention and education efforts in general have been underfunded, erratic, uncoordinated, confusing, and timid. The results have been correspondingly meager. Many people engaging in high-risk behaviors do not understand or acknowledge their risk and have not changed their behavior. For many, AIDS has

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* In this report, the term "AIDS" (Acquired Immunodeficiency Syndrome) is sometimes used to refer to the spectrum of illness of HIV disease, of which AIDS is the most serious and final stage. In time, "HIV disease" may replace "AIDS" as the term most familiar to the public. However, "AIDS" is currently better known.

become just another unpleasant fact of modern life, one easily relegated to the background.

As we enter the next phase of the HIV epidemic, new therapeutic alternatives offer an opportunity to bring asymptomatic HIV-infected people into settings where they will receive ongoing medical care and counseling to prevent further HIV transmission. The experiences of previous prevention programs should help us reframe the messages and refine the educational techniques to maximize effectiveness.

The National Research Council of the National Academy of Sciences concluded:

> The HIV/AIDS epidemic is partly a social phenomenon, and the major weapons that are currently available to contain it seek to change the behaviors that spread the disease. Even if fully effective therapies were to be found, it is likely that there will be a continuing role for behavioral intervention. It is more than 40 years since effective drugs against syphilis and gonorrhea became widely available, but those diseases have not been eradicated in the United States. . . Improved understanding and prevention of the behaviors that spread HIV/AIDS will be needed -- not only in the short run, however many years that may be, but in the decades that follow any medical breakthrough as well. [1]

Just as there is no therapeutic "magic bullet," there is no educational panacea. Early optimism, even naivete, which saw prevention as a simple matter of telling people to stop risky sexual and drug-using behaviors, has given way to a sober recognition of the complexities of changing human behavior. Clearly, there is need for a deeper understanding of intimate, private, and largely unexplored aspects of life. Prevention is a complex problem that calls for changes in deeply rooted attitudes and behavior by individuals, partners in sexual and drug-using relationships, and by society in general. Nothing less than a shift in basic social attitudes is required. It has taken twenty-five years for a widespread, but still incomplete, change in attitudes toward cigarette smoking to occur. In the case of HIV, we cannot wait that long.

But let us not replace naive optimism with cynical pessimism: difficult though it may be, the goal of preventing transmission of HIV can be furthered through education directed at the general public, at communities and small groups, and at individuals and their sexual and drug-using partners.

Infected individuals bear the primary responsibility of preventing transmission because only they have the ability to control risky behaviors. But the responsibility does not lie with them alone. By definition risky behaviors involve two people, and the relationship between them. Either partner may initiate behavior change, but it must be mutually acceptable in order to be sustained. Uninfected persons must learn

how to protect themselves, since not all those who are infected know that fact or have fully accepted their responsibilities to prevent transmission. Family, friendship, and community ties are needed to create and maintain strong social supports for responsible, restrained individual and couple behavior. Society in general has a responsibility to provide the kinds of programmatic and social services that will be required to maintain responsible behavior over long periods.

The social climate in which risk-reduction messages are communicated is an important factor in their acceptability. The stigma and discrimination surrounding AIDS must be eliminated not just because of the resultant injustices but because negative attitudes and actions deter prevention efforts. Because of the stigma, those who engage in risky behavior may deny their risk, even to themselves, and may avoid counseling and other educational efforts.

Beyond a broad social recognition that AIDS and HIV disease affect all segments of society, either directly or indirectly, and the development of a compassionate, caring response to meet the needs of those who become infected and ill, communities must develop specific programs to meet the challenge of prevention. These programs should be based on scientific and medical knowledge and should be sensitive to the values, culture, and practices of affected groups. In the richly varied setting of communities in New York City and New Jersey, the basic educational messages about prevention can and should be presented in different ways. Just as each group has the obligation to construct its own prevention program, each should accept the rights of others to focus their prevention efforts differently.

AIDS Education for the Future

Based on the experiences of those involved in AIDS education and the research conducted so far, these conclusions should guide future efforts:

1. **To be effective, educational efforts must contain several key elements:**

a. Educational messages should be accurate, consistent, cumulative, and long-term. No single message or intervention will achieve the goal of stopping the spread of HIV. Messages need to be repeated and to come from many different sources before they will have the desired impact. They should be clear and comprehensible, using language and terms that are easily understood by the particular audience.

b. Educational messages should be communicated through all appropriate media and through numerous forms of one-to-one and small group contact. Messages can be delivered through television, radio, newspapers, magazines, printed materials, audiovisual aids, telephone hotlines, comic books, drama, music, story telling, poetry,

role playing, and other ways. They can be delivered to a mass audience, to specific communities, to small groups, and to individuals. Particularly important are forums in which individual or group counseling can occur, such as support groups, peer counseling, individual counseling, and so on. Innovative methods of communication can reach those who are difficult to reach through traditional forums. Some examples of such programs are described in the appendix to this report.

c. Educational messages should be developed by and communicated by persons who are knowledgeable, credible to the audience, and sensitive to the emotional and cultural nuances of the information. The messenger is often as important as the message. People will not respond even to the suggestion of risk if the person conveying that unpleasant message is perceived as insensitive or unaware of prevailing mores. Education programs aimed at minority communities must be developed by leaders in those communities, in consultation with others where desired. Community-based organizations (CBOs) are the most effective vehicles for developing and implementing education programs. The New York City AIDS Task Force has recommended that the public and private sectors provide "additional funds for CBO technical assistance programs, which include program development and evaluation, financial management, grantsmanship and development of educational materials." [2]

d. Effective educational messages may arouse a certain level of fear; however, other approaches, including positive alternatives to risky behavior, social acceptability, and humor, are often more effective. Arousing fear is relatively easy and fear of infection may be the first step in motivating behavior change. But these messages should always be combined with specific and productive advice about how to counter the danger. Particularly in the new era of early therapeutic intervention, it is important to stress that HIV infection is a treatable disease, although not yet a curable one.

An overemphasis on fear-based messages can be counterproductive. Fear may indeed engender some preventive behavior, at least in the short term, but it can also encourage denial on the part of some who are at risk. This approach can also lend support to the kinds of coercive measures that lead to stigma and discrimination, which ultimately discourage behavior change in those most at risk. [3]

John Gagnon, professor of sociology at the State University of New York at Stony Brook, warns about one unintended consequence of linking studies of sexuality with disease: "Sex itself can become confused with disease and being sexual in various ways becomes treated as an illness or as evidence of illness." [4]

e. Education and prevention programs targeted at specific populations should be linked to the provision of appropriate services. The availability of early therapeutic

intervention makes it critical to provide medical, social service, and emotional support to people who are HIV-infected. These services should include ongoing counseling and support to prevent further transmission. Individuals will be more motivated to change behavior if they are receiving concrete benefits in the settings where the prevention message is delivered. For example, establishing a coordinated system of primary medical care, drug treatment, and HIV prevention to drug users offers the triple benefit of improving their general health, eliminating or reducing their drug use, and providing counseling and motivation to prevent transmission. [5]

Other concrete services, such as the treatment and prevention of ulcerative sexually transmitted diseases (STDs) and the availability of expanded contraceptive services are also necessary complements to educational programs. Recent increases in primary and secondary syphilis, chancroid, and resistant gonorrhea among inner-city heterosexuals are not only worrisome in themselves; they facilitate the rapid dissemination of HIV. Those who suffer from these diseases appear to be at greater risk for HIV, both for biological reasons and because of the risk behaviors associated with STDs and HIV. Family planning centers are a natural place to provide HIV counseling, as well as contraceptive services. Unfortunately, funding for both STD control and family planning has been reduced in recent years; adequate resources for these efforts will aid in preventing HIV transmission. [6]

Anonymous or confidential counseling and HIV testing programs can also play a role in risk reduction. Access to such programs should be readily available, and appropriate follow-up referrals and counseling should be provided. It is particularly important that counseling be offered to people whose HIV antibody tests are negative so that they will not draw incorrect inferences about their prospective risks and so they can learn to modify the behavior that put them at risk in the first place.

2. Public education campaigns providing accurate, up-to-date, and clearly stated information about AIDS should be a continuing, coordinated, and high-priority effort.

Surveys among the general public and specific groups have shown an increase in knowledge, albeit with some significant continuing misunderstandings, but relatively little change in behaviors or attitudes. Public awareness about AIDS must remain high in order to create a social context that will support responsible behavior and discourage discrimination and stigma.

Beginning in August 1987, the National Center for Health Statistics (NCHS) has included a special set of supplemental questions on the adult population's knowledge and attitudes about AIDS in its National Health Interview Survey (NHIS). A comparison of data from August 1987 to August 1988 indicated that the most

substantial increase in knowledge related to HIV transmission. The proportion of adults who answered that it was "definitely true" that AIDS is an infectious disease caused by a virus increased from 44 percent to 64 percent. The percentage who said that it was "definitely true" that a pregnant woman can transmit HIV to her baby increased from 65 percent to 76 percent. In 1987, 35 percent of adults responded that it was "very unlikely" that a person could become infected with HIV by working near someone with it, and 18 percent said that it was "impossible." Those percentages increased in 1988 to 40 percent and 27 percent, respectively.

These overall increases coincided with a national multimedia public awareness campaign. The impact of one element of the campaign -- mailing of the Surgeon General's brochure, "Understanding AIDS," to 107 million American households -- is being evaluated. [7] That mailing elicited 250,000 phone calls to a special hotline, but over half (51 percent) of adult Americans polled by the Gallup organization said that they did not read the report, either because they did not remember receiving it or because they chose not to look at it when it arrived. [8] The most recent NHIS data, covering January-March 1989, showed a decline from the previous period (from 28 to 24 percent) among adults who reported having read any brochures or pamphlets in the month preceding the interview. There was a smaller decrease in the percentage of adults who said that they had ever read any brochure or pamphlet on AIDS (from 65 percent in December to 63 percent in January-March).

Preliminary data for January - March 1989 showed modest improvements in knowledge: the percentage of adults who thought it was definitely false that "looking at a person is enough to tell if he or she has the AIDS virus" increased from 66 percent to 70 percent. The proportion of adults who thought it very unlikely or definitely not possible to become infected with HIV by "living near a hospital or home for AIDS patients" increased from 80 to 83 percent. When the question was asked about the risks of transmission from "working near someone with the AIDS virus," 71 percent said it was either "very unlikely" or "impossible," up from 67 percent in 1988. [9]

Researchers in the 1988 NHIS survey also examined knowledge and attitudes of black and Hispanic Americans. Interpretation of ethnic differences should be approached with caution. Nevertheless, patterns of knowledge and attitudes about AIDS and HIV are essentially the same as for the United States population as a whole, within categories of age, sex, and education level. Black adults scored as well as whites of comparable demographic characteristics on questions relating to the risks of HIV transmission through shared needles, perinatal events, and sexual intercourse. However, black adults were 5 to 10 percentage points less likely to recognize the low or nonexistent risks associated with casual contact with infected individuals. The proportion of black adults who considered maintaining a monogamous relationship

with a seronegative individual to be a very effective means of protection against HIV infection was considerably lower (71 percent) than the percentage among whites (84 percent). [10]

A similar analysis of data about the views of Hispanic Americans found the highest levels of knowledge among the young and the well-educated, a trend that is mirrored in both the black and white communities. Hispanics were somewhat less likely than white adults to identify the low risks of casual transmission in the workplace, but the differences were not as marked as with black respondents. Ten percent of Hispanics thought that condoms were not at all effective against HIV, twice the proportion of non-Hispanics, and 2 percent higher than among blacks. The percentage of Hispanics who thought that monogamy with a seronegative person was an effective means of prevention was exactly the same as for blacks. [11]

Eleanor Singer, Theresa F. Rogers, and Grethe Lunde at Columbia University charted trends in knowledge, attitudes, and behavior in response to AIDS from 1985 to 1987, using 15 nationwide sample surveys conducted by five private organizations -- ABC/*Washington Post,* CBS/*New York Times,* NBC/*Wall Street Journal,* Gallup, and the *Los Angeles Times.* [12] (According to David Kanouse of the Rand Corporation, all national survey data underrepresent the minority communities most at risk.). In their examination of knowledge about transmission, they found "widespread accuracy at the extremes, with some confusion about intermediate modes." For example, nearly everyone knew that AIDS can be transmitted by homosexual or heterosexual contact, by sharing intravenous needles, and by blood transfusions. They also knew that they could not contract AIDS by being in the same room with someone with the disease. But, substantial numbers of people did not believe the public health experts who say that HIV cannot be transmitted by behaviors such as kissing, sharing a drinking glass, and eating food prepared by someone with AIDS. In general, educational level has the greatest effect on the accuracy of knowledge. Nonwhites, who are at statistically greater risk than whites for transmission through known routes, are also more fearful of transmission through undocumented routes such as toilet seats and drinking glasses. Older people (whose risks are statistically lower) are also more fearful of these perceived routes of transmission, perhaps because they have lived through an era of infectious diseases spread through close, nonsexual contact.

Of particular interest are the study's observations about responses from New York City residents. New Yorkers, who are at greater risk by virtue of living in the city with the highest number of HIV-infected people in the United States, are generally less accurate than the general population in their assessment of the riskiness of kissing, sharing a drinking glass, and other undocumented modes of transmission. Since these findings are similar for nonwhites it is possible that the primary variable is not residence in New York City, but race.

Whichever is true, the finding clearly indicates a continuing need for public education messages in New York City about how HIV is and is not transmitted. The study concluded that:

> Subgroups at greater objective risk are also more likely to report having taken useful precautions against AIDS, such as changing their sexual behavior and using a condom. At the same time, however, they are less knowledgeable, more likely to attribute risk to modes of transmission that are really innocuous, and less likely to attribute risk to those that are truly hazardous.

In the summer of 1988, the Public Agenda Foundation conducted a series of focus group discussions in six cities (including New York) to explore the public's perspective on the public policy dimensions of AIDS. The participants reflected a cross-section of the population in terms of age, race, sex, and education. Compared to a similar study conducted in 1985, fewer people saw AIDS as a direct threat to themselves (19 percent in May 1988 compared to 42 percent in 1985). In January 1988 only 6 percent were "very concerned" about getting the disease. Many people, however, were concerned about the younger generation, and a few were worried about the impact of AIDS on society as a whole. [13]

Although the respondents believed that AIDS would be limited to certain groups of Americans, they expressed strong support for research to find a vaccine or cure. Most of the respondents did not view AIDS in predominately moralistic or religious terms, nor did they think that a return to what the study authors termed "a pre-1960s morality" was practical.

Although respondents generally expressed compassion for people with AIDS, their concern did not extend to drug users with the disease, whom they viewed with great hostility. Several suggested that society should not make any special effort to assist drug users; in their view drug use is a matter of personal choice, not an addiction or the result of poverty and deprivation. By contrast, the focus group members tended to see homosexuality as an unalterable condition, and homosexuals as a group that makes economic and cultural contributions. (This differs with other studies that show considerable intolerance, including harassment and violence, targeted at homosexuals.[14])

Most respondents were reasonably well informed about the disease and modes of transmission. They were comfortable in talking about AIDS and wanted the media to be more, rather than less, explicit. However, many respondents did not understand the difference between having AIDS and being HIV-positive. Most assumed that all those carrying the virus show visible symptoms and face imminent death. (This misconception can be dangerous for those engaging in risky behaviors

since it leads to ineffective partner selection strategies.) Virtually none of the respondents had any understanding of the likely costs of treating AIDS.

In their review of public opinion surveys, Robert Blendon and Karen Donelan of the Harvard AIDS Institute found a high level of intolerance and willingness to discriminate against people with AIDS. Even though only 11 percent of Americans say that working with someone with the disease is a likely way to contract AIDS (a decline of two-thirds from 1985), a quarter of Americans say that they would refuse to work with someone with the disease. Similarly, only 10 percent believe that children can contract AIDS from sitting next to a classmate with the disease, but one-third of parents say that they would withdraw their child from school if a child with AIDS were admitted. [15] While this finding may not accurately predict what parents would actually do in such a situation, it does reveal a high level of fear and concern.

Another reason that AIDS education for the general population must continue is to assure the protection of the nation's blood supply. The public must be reminded again and again that donating blood cannot transmit HIV. But they must also be reminded that if they have a risk factor for HIV transmission, they should not donate blood. A study of 173 New York Blood Center donors who were found to be seropositive showed that more than 20 percent were women, a much higher percentage than expected. Only one of the 38 female donors had a history of intravenous drug use. Many participants were not aware that they were at risk for HIV infection. Only one third of confirmed seropositives had indicated that their blood was to be used for "studies only," removing it from the transfusion supply regardless of antibody screening results. Failure to self-exclude and failure to understand that their blood would be tested for HIV was more common among donors with less education. [16]

Another study among blood donors in Washington DC found that a small number of persons with HIV infection continue to donate blood. The authors suggest that "the majority of our HIV-infected donors understood the definition of high-risk behavior but did not view themselves as having engaged in such behavior." They conclude that "both donor-education policies and interview strategies need to be strengthened." [17]

To sum up, the public's knowledge about AIDS and HIV transmission has improved considerably, but there are still gaps in understanding about key points. People with less than a high school education and nonwhites are not as well-informed as their better-educated, white counterparts. Despite better information and lowered perceptions of personal risk from casual contact, many people continue to have negative attitudes about people with AIDS and to fear contagion through casual

contact. Thus, stigma and discrimination have not diminished, and may in fact have hardened over time.

3. The mass media have an important role to play in communicating basic information and in creating a social context in which targeted messages are more likely to be acceptable.

Most Americans receive their only information about AIDS from the mass media -- television, radio, newspapers, posters, and magazines. General awareness of the disease and its severity, as well as its primary modes of transmission, is a direct result of media attention to the epidemic. In the NHIS survey data cited earlier, 86 percent of all American adults reported having seen public service announcements (PSAs) on television, and 48 percent had heard them on radio by July 1988. The proportion was highest for the 18-to-49 age group and for those with 12 or more years of school. About one-quarter of adults stated that the announcements they had seen or heard were part of the United States Public Health Service's "America Responds to AIDS" series. [18] In the January-March 1989 data, black adults and men were more likely than white adults and women to have heard PSAs on the radio. [19]

The impact of the mass media on the public's attitudes toward AIDS and on risk reduction behaviors is less readily quantified; however, it seems clear that the mass media have been less influential in changing attitudes and behaviors than in imparting information. In part, this is because the mass media are most effective at selling specific products. The only specific product involved in AIDS risk reduction is condoms, and most networks and local stations refuse to accept condom advertising. In October 1988 the three major networks did agree to run public-service advertising that promotes the use of condoms to prevent AIDS, but there has been no follow-up on frequency or impact. [20] The main emotional response generated by mass media campaigns (again with some exceptions, such as the "America Responds to AIDS" campaign) appears to be fear. As already noted, fear can be a useful motivator, but unless it is linked to a protective action, the audience tends to dismiss or deny the personal relevance of the threat.

Mass media messages must be simple, but even simple messages acquire some of their meaning from the context. As Sandra Wallman, a British anthropologist, points out, in discussing a poster with just two words -- "STOP AIDS":

> . . . some will not see that the letter "O" is a condom, some will find it offensive, and probably a majority will decide the message is not addressed to them -- whether because they have no access to condoms, or because they consider that AIDS is not a threat to "people like us." Even people who get the message and fully understand its implications may not be able to act on it; there is no way they can

separate that understanding from the complex of other things happening in their lives. [21]

Even when there have been creative mass media campaigns aimed at changing behavior, the infrequent and uncontrolled scheduling that accompanies any campaign dependent on public service time has dampened the impact. The success of a commercial campaign depends not just on choosing the right message and aiming it at the right audience but also on frequent repetition.

Saatchi and Saatchi DFS Compton has analyzed the impact of the advertising campaign it created for the New York City Department of Health. Ads targeted at 18-to-34-year-old single heterosexuals appeared in newspapers, and on subway posters and on television and radio from October 1987 to February 1988. A follow-up television survey of the target audience indicated a high recall (86 percent) of advertising about how to prevent getting AIDS. The ad containing the slogan, "If you think you can't get AIDS, you're dead wrong," had the highest recall (89 percent). Young singles also report having changed their attitudes toward condom use, more often believing that people should carry and use condoms. However, young singles did not report significant behavior changes. This suggests that behavior may be controlled by situations or social norms, not just a belief that condoms are a good idea. Most still do not regularly use condoms when having sexual intercourse. [22]

An extensive anti-drug media campaign has been carried out in the past few years by the Media-Advertising Partnership for a Drug-Free America. Its television commercials have run more than 20,000 times; the estimated cost of the first year's donated time and space exceeded $150 million. A survey of 7,000 respondents after the first year's campaign showed that in the ten markets where media exposure was high (on the average four times greater than elsewhere), respondents' attitudes showed "far greater improvement" (i.e., were less favorable toward drug use) than in the balance of the united States. However, black and Hispanic parents underestimated their children's use of and exposure to illegal drugs, and teenage attitudes showed the least improvement. The sponsors concluded that "Greater advertising exposure results in greater attitudinal shifts. The more media time and space put behind our efforts, the faster denormalization of drug use can be accomplished. . . Real success depends on the size of our commitment and perseverance over time." [23]

In addition to mass media campaigns, entertainment programs can build in AIDS awareness through plot and character development. In supporting a campaign in which characters in television dramas act as designated drivers to prevent drunken driving, Grant Tinker, a former chairman of NBC and an independent television producer, said: "There's a tune-out thing that occurs when a public-service spot

appears. If a message is in the body of a program coming from the mouth of a character you like and pay attention to, it can really have a tangible result." This model, developed by the Harvard Alcohol Project, frankly recognizes the use of television as an instrument of social change. If successful, this approach could be applied to attitudes about AIDS and risk reduction as well. [24]

The New York-New Jersey area is overloaded with communication by the media, making it easy for AIDS messages to get lost. Various campaigns have at times competed with each other for PSA scheduling; messages may be confusing or conflicting. What is especially needed now is an agreement among media owners, program coordinators, and AIDS specialists to develop a few central themes and a coordinated approach to communicating them. These themes can reinforce the modes of transmission, the importance of early intervention for those who are at risk, the need for compassion for those who are ill, and the need for public and private support for resources to cope with the many manifestations of HIV.

4. Targeted education campaigns for gay men should be continued and supported, so that those who have changed behavior can sustain those changes and those who have not can be motivated to change.

In what is perhaps the most dramatic health behavior change in recent history, gay men have adopted "safer sex" practices, with a resulting sharp decrease in the incidence of new infections. In a review of 30 studies in the United States and six in the United Kingdom, Marshall H. Becker and Jill G. Joseph of the University of Michigan School of Public Health found "rapid, profound, but expectably incomplete alterations in the behavior of both homosexual/bisexual males and intravenous drug users." The measures of risk reduction in sexual behavior were number of sexual partners, frequency of anal intercourse, and use of condoms and/or spermicides.

The studies also showed that risk reduction was more frequently accomplished through modifying, rather than eliminating, sexual or drug-using behavior. While the trend toward risk reduction was clear in the overall data, the behavior of some individuals varied markedly; sustaining safe practices proved difficult for many. In looking at potentially vulnerable heterosexual adolescents and young adults, and at urban minorities, Becker and Joseph found much less evidence for behavior change. [25]

A thorough review by the Congressional Office of Technology Assessment (OTA) reached essentially the same conclusions. By 1988, the OTA reported, less than 2 percent of uninfected homosexual men in San Francisco were becoming infected annually. [26]

John Martin of the Columbia University School of Public Health has conducted the most extensive research so far on gay men in New York City. In a longitudinal study of 745 self-identified gay men -- mostly white and college-educated -- Martin compared recent behavior during a one-year period with behavior recalled during a year prior to learning about AIDS. Men who had sex away from their homes reported decreasing the number of partners from 36 before AIDS to eight after AIDS. The number of reported receptive anal sex episodes -- the riskiest form of sexual activity -- decreased by 75 percent, and the use of condoms by partners during these episodes increased from 2 percent to 19 percent. [27] These conclusions must be viewed with caution, since the sample is not representative and the findings are based on retrospective recall.

In a follow-up report using the same data, Martin described seven distinct risk categories. The most extreme was men who had multiple partners at home or elsewhere and had engaged in high-risk acts. This behavior pattern decreased by 26 percent in the two time periods being compared. The least common behavior change was choosing to become celibate (1 percent). The most frequently changed behaviors were restricting sexual activity to lower risk behaviors and eliminating sex outside the home. [28]

In his most recent report, based on interviews with 357 men in his research cohort and on their HIV antibody test results, Martin found that "Cessation of unprotected intercourse is associated with lowered risk of HIV infection." Becoming monogamous was associated with a small decrease in the odds of HIV infection. By 1986-87, Martin reports, 82.9 percent of the sample either abstained from receptive anal intercourse entirely, or used a condom every time intercourse occurred. Nevertheless, nearly 20 percent of the sample continued to engage in unprotected receptive intercourse. Martin concludes:

> Continued educational messages are clearly needed for urban gay men in order to sustain and reinforce changes that have been made, as well as encourage those who have not changed to do so, since such changes may indeed make a difference in risk of HIV infection. [29]

Moreover, studies that have examined sexual behavior among gay men have looked at a specific group over time. The population of gay men changes, as young men become sexually active, as older men change their sexual behavior, and as gay men move to New York or New Jersey from parts of the country with lower HIV prevalence. These men represent a new and different audience for education programs.

The Centers for Disease Control's funding guidelines for prevention projects in effect prevents federal funding of explicit education targeted at gay men. The

guidelines state that terms or descriptions of dangerous behaviors and less risky ones, even when used to communicate with a specific group such as homosexual men, must be those that "would be judged by a reasonable person to be inoffensive to most educated adults beyond that group." [emphasis added] This means that the standards of the larger society outweigh the need for meaningful communication for those at risk. A further barrier to federal funding states that none of the funds available from the CDC can be used to provide AIDS education, information, or prevention materials and activities that "promote or encourage, directly, homosexual sexual activities." That is, under these guidelines the only acceptable message to gay men is to become abstinent.[30] As already noted, this is precisely the least likely message to be heeded by gay men.

In sum, there are initially promising indications of behavior change among those gay men at highest risk. However, there is no room for complacency. Life-long behavior change is required for life-long prevention, although there are also clear benefits from temporary behavior change. There is a continuing need for sensitive, supportive models of education that promote continued adherence to less risky behaviors. In addition, substantial minorities of gay men at risk have not yet changed their behavior, and even more intensive and creative efforts are needed to encourage them to do so.

5. Drug users and their sexual partners are difficult populations to educate but they should not be considered "unreachable."

Drug users are, according to the conventional wisdom, uneducable, self-destructive, and unconcerned about their own health or that of others. While the difficulties of gaining the trust and cooperation of drug users and their sexual partners cannot be denied, considerable evidence indicates that this conventional wisdom is wrong. While some subpopulation of drug users will probably be unresponsive to appeals of any kind, a much larger group is aware of AIDS, has already demonstrated the ability to modify at least some forms of risky behavior, and is eager for treatment of their drug problems.

The Becker and Joseph study cited earlier found substantial, albeit incomplete behavior changes among drug users, as measured by the avoidance of sharing needles or syringes, and the use of bleach to sterilize drug paraphernalia. [31]

The National Cancer Institute, the National Institute on Drug Abuse, and the State Department of Health in New Jersey conducted knowledge assessment surveys in 1984 and 1985 of IV drug users in New Jersey. The first survey of 1,000 IV drug users found that almost all had heard of AIDS. More than 95 percent knew that IV

drug users were at increased risk of becoming infected, and 90 percent were aware of the most severe symptoms. An equal percentage correctly identified the means of reducing risk of infection. [32]

A similar survey conducted the following year among 577 clients entering drug treatment programs in New Jersey found similarly high levels of knowledge about transmission and symptoms, but a lack of awareness of some methods for preventing transmission (such as using bleach to sterilize drug paraphernalia). Almost half of those entering drug treatment cited a fear of AIDS and other diseases as their motivation.

On the basis of these findings, the New Jersey Department of Health has initiated several strategies for educating drug users. Indigenous health workers -- former drug users who are enrolled in a methadone maintenance treatment program or who have graduated from drug-free programs -- are employed as street workers to give information to addicts, particularly those in the riskiest settings like shooting galleries. The results of the 1985 survey indicated that nearly one in six drug users had received some information about AIDS from these health workers. In addition, the street price of sterile needles and syringes had increased, a reflection of the increased demand among IV drug users responding to the warnings about shared needles.

The New Jersey Department of Health also initiated a voucher campaign. Street workers periodically passed out vouchers to addicts on the street offering free and immediate detoxification treatment. Over 80 percent of the vouchers were redeemed, indicating a high level of interest. (All treatment programs in New Jersey have charged their clients since 1981. The fee for an initial assessment and detoxification, ranges from $50 to $150.) Forty-four percent of the addicts redeeming their vouchers had never been in treatment before and 20 percent remained in treatment after the initial detoxification. Each voucher client received a one-hour education session and a pre- and post-test. Scores increased significantly after the educational session.

In New York City, all 50 methadone maintenance patients interviewed by researchers at the New York State Division of Substance Abuse in 1984 had considerable knowledge about AIDS; 93 percent knew that IV drug use is a means of transmission. Furthermore, 50 percent of the subjects had changed some behavior to avoid the disease; the most common changes were increased use of clean needles and/or cleaning needles (31 percent) and reducing needle sharing (29 percent). More than half also reported that friends had changed behavior as well. [33]

Other researchers, such as Peter Selwyn of Montefiore Medical Center, have found similar levels of knowledge and the beginnings of behavior change. [34]

As support for the validity of these studies, Don Des Jarlais notes other studies that have shown a large-scale increase in the demand for sterile needles and syringes for injecting drugs. A market in "counterfeit" sterile needles (used needles repackaged as new) has sprung up to meet the demand. Des Jarlais and Friedman conclude:

> Studies of AIDS risk reduction show substantial proportions of IV drug users changing their behavior to avoid exposure to HIV. . . The primary forms of risk reduction are increasing the use of sterile equipment, reducing the number of needle-sharing partners, and reducing the frequency of injection. These behavior changes are very similar to the frequently identified behavioral risk factors associated with HIV exposure, suggesting that they should be effective in at least slowing the spread of HIV among IV drug users. [35]

Richard Conviser and John H. Rutledge offer some helpful guidelines for risk reduction education:

- Risk-reduction messages have to be delivered in oral as well as written form.
- These messages must be delivered by people with whom IVDU can identify -- a particular challenge when the messages originate with government agencies.
- The messages should be nonjudgmental in tone, and caring rather than punitive.
- They must be sensitive to the ethnic, cultural, and racial characteristics of their audiences.
- They must pose alternatives to current practices that are both feasible and appealing.
- They must be carried out in an ongoing way, rather than being allowed to tail off after an initial effort. [36]

6. Efforts to change risky behavior to prevent further transmission of HIV face significant barriers.

These barriers include researchers' and program developers' lack of knowledge about many of the behaviors that are most likely to spread HIV (who engages in them, why, and how they might be motivated to change); community-wide and individual resistance to acknowledging risk and modifying behavior; the stigma of AIDS; the private nature of sexual and drug-using behaviors; the fact that by definition these behaviors involve two people; a reluctance to use condoms, particularly among many at highest risk; and the countervailing pressures of other forces in society (advertising and media that celebrate risk-taking in driving, athletics, sexual behavior, or alcohol or cigarette use, for example).

Designers of education programs on AIDS must build their ships while they sail them. As June Osborn, M.D., dean of the School of Public Health at the University of Michigan and chair of the new National AIDS Commission, puts it,

> We could halt the spread of the virus were it not for the territory on which it has chosen to do battle. We now know more about the virology and pathology of HIV than any other pathogen. But the elegant advance of biomedical science has not been matched in behavioral science. We are condemned to citing "Kinsey, 1949." [37]

In his review of the gaps in knowledge, John Gagnon notes that,

> If we knew what the sexual practices of various groups in the society were and had explanations for why persons conduct themselves in certain ways, we could employ the usual methods of social science to monitor how behavior changes as both the epidemic and its representations change. Both the baseline data and adequate theories of sexual conduct, however, are in short supply. [38]

These deficiencies in knowledge, Gagnon continues, apply to gay men, bisexual men, female prostitutes and their clients, adolescents, drug users, and heterosexuals -- in other words, everyone who is sexually active. Future research efforts should be directed not just to individuals but also to the social networks in which sexual relationships occur. Gagnon writes, ". . . it becomes important to know numbers of sexual partners, frequency of sexual activity, and sexual techniques in each type of contact as well as the social attributes of sexual partners." [39] Research studies that could provide the basic knowledge needed to construct educational programs are controversial, and are unlikely to be funded by any government body. A large-scale federally funded survey of sexual practices that would have cost $11 million failed to gain approval of the House Appropriations Committee in August. Congress had already appropriated $2 million for a pilot study to see whether a national sex survey is feasible. However, HHS Secretary Louis Sullivan has not approved the project. [40]

The black community, which has been particularly hard hit by AIDS, has been reluctant to grapple with issues relating to the epidemic and is only now responding with increased vigor. In the view of Harlon L. Dalton, a professor of law at Yale University and a member of the new National Commission on AIDS, five overlapping factors explain the hesitation within the black community:

> The first is that many African-Americans are reluctant to acknowledge our association with AIDS so long as the larger society seems bent on blaming us as a race for its origin and initial spread. Second, the deep-seated suspicion and mistrust many of us feel whenever whites express a sudden interest in our well-being hampers our progress in dealing with AIDS. Third, the pathology of our own homophobia hobbles us. Fourth, the uniquely problematic relationship we as a community have to the phenomenon of drug abuse complicates our dealings with

> AIDS. And fifth, many in the black community have difficulty transcending the deep resentment we feel at being dictated to once again. [41]

The stigma associated with AIDS carries special force in minority communities but is by no means limited to them. The link between AIDS and homosexual behavior and drug use has heightened the stigma traditionally associated with sexually transmitted diseases. Karolynn Siegel and William Gibson, from the Department of Social Work of Memorial Sloan-Kettering Hospital Cancer Center in New York, observe that

> the need to dissociate oneself from AIDS or even from the implication that one could possibly be infected may be very great. If introducing a condom might be construed to mean that one acknowledges that one may be at risk, individuals may be unwilling to do so. Further, if doing so is felt to impugn the character of one's partner, one also may resist the use of condoms. The stigma associated with AIDS may also make individuals unwilling to seek out information -- including prevention-related information -- about the disease. The wish to deny that the problem has any personal relevance is so strong among many that it may serve as a barrier to their obtaining needed information about the disease. [42]

Siegel and Gibson describe several other barriers to behavior modification. Partly as a result of denial and confusion about risk behaviors, many people have a faulty appraisal of their own risk. A common defense mechanism is a sense of personal invulnerability to health threats. People also selectively interpret advice about risk reduction. For example, some people, following public health education messages, have reduced their numbers of sexual partners, but, ignoring the same messages, have not used condoms. Reducing the number of partners has limited effectiveness unless the chosen partners are uninfected. Having unprotected sex with a single infected partner poses a risk of transmission; having unprotected sex with a host of uninfected partners does not. Similarly, many women have understood the message that drug users can transmit HIV sexually to mean only currently active drug users: yet a former drug user may have become infected years ago and may transmit the virus unless condoms are used. [43]

Some of these misunderstandings arise from ambiguity or unfamiliar terminology in the educational messages themselves. The most common is the confusion between "risk group" and "risk behavior." People who do not fall into one of the main categories of people affected by AIDS -- homosexuals and drug users -- often see themselves as free of risk, regardless of their behavior. Thus, heterosexuals who engage in unprotected intercourse, particularly anal intercourse (either out of preference or as a form of birth control) are at risk because of this behavior. Men who have sex with other men but do not identify themselves as gay -- a not uncommon pattern in both white and minority communities -- are also at risk.

Another confusing piece of advice is to avoid "multiple partners." Public health educators use the term to mean two or more partners within a specified time period, such as a year. But one woman who steadfastly denied that she had "multiple sexual partners" insisted: "I only have sex with one person at a time." Others do not confuse "multiple partners" with group sex, but believe that having a single partner for a relatively brief time, followed by another partner, and so on, constitutes "monogamy." [44]

A third confusing term is "sexually active." Because of the early association of AIDS with the practice of anonymous sex with many partners, a pattern that defined the sexual behavior of some gay men, many people equate "sexually active" with "promiscuous." That term is subject to interpretation and is burdened by such negative connotations that many people do not believe that warnings apply to them, regardless of how many partners they have. A fourteen-year-old girl came up with an even more idiosyncratic interpretation of "sexually active." When a researcher asked her if she was sexually active, she replied, in all seriousness: "No, I just lie there." [45]

Even when people understand the messages, they may be skeptical about information from public health experts. In the NHIS survey in June 1988, 28 percent of respondents doubted the accuracy of the general AIDS information produced by federal public health officials, and 16 percent were skeptical about their advice on avoiding AIDS. [46]

Condom use presents particular barriers. Impediments to the use of condoms for contraception or to prevent sexually transmitted diseases include the belief that condoms interfere with sexual pleasure, that they inhibit spontaneity, that they are ineffective or unreliable, that they are embarrassing to buy, and that they are offensive to one's partners.

Columbia University researchers Singer, Rogers, and Lunde reviewed public opinion poll responses to questions about condom use and changes in sexual behavior. In the only survey (Gallup) that asked about condom use, about half the responding 18 and 19-year-olds and half of all nonwhites reported their use (or, for women, asking their partner to do so). Men were more likely to report condom use than women. This question was asked, in different forms, in November 1986 and in June 1987 but there were no changes in condom use.

Responses to the question about general changes in sexual behavior showed that the youngest people, the unmarried, and men were more likely to report changes than older people, married people, and women. Fewer people (18 percent of nonwhites, and 22 percent of those aged 18 to 24) reported changes in sexual

behavior than in condom use. As with the responses to questions about condom use, there were no changes over time.

Condom use must be acceptable to both partners, making it even more difficult to overcome the negative image. In the current jargon, safer sex practices, including condom use, must be "negotiated." In negotiations between women and men, particularly young people and minorities, women are seldom equal partners. For many poor, minority women, sex is not so much a pleasurable activity as a commodity, her only asset in establishing or maintaining a relationship with a man or in acquiring emotional or financial support. [47] Such an imbalance of power means that women who try to change the terms of the sexual relationship do so at their own peril. Psychologists Vickie M. Mays and Susan D. Cochran of the University of California, Los Angeles, and California State University, Northridge, respectively, report that "a small subset of Black and Latina women experience physical and verbal abuse in response to requests for their partners to use condoms." Even those who do not encounter violence risk losing the relationship.

Public health messages advising women to discuss sexual practices and encouraging condom use fail to reflect the reality of these women's lives. Mays and Cochran say: "Traditional Hispanic women are expected to be modest, faithful, and virginal. Cultural norms dictate that these women enter marriage with little knowledge about sexual practices and rely on their husbands for the acquisition of this knowledge. It is also not generally normative to discuss sexual matters." Moreover, they say:

> When a poor ethnic woman meets a man of unknown background whose current presentation appears to be that of a clean-cut, upwardly mobile man, she does not ask questions. [48]

Young white women are also resistant to condom use. A study of 200 such women who came to a primary care physician's office showed that 64 percent were sexually active. Virtually all of the women said they got their information about AIDS from television but that friends had the greatest influence in their willingness to change sexual behavior. Just over a quarter of the partners of the women who were sexually active used condoms; the most commonly stated reason for not using condoms was that there was no need to do so, even among women with a history of sexually transmitted diseases. [49]

Another barrier is that condom use appears to be most difficult with an intimate and trusted partner. Prostitutes are more likely to use condoms with clients (unless the clients object or pay more to forego condom use) than with their boyfriends; they are most at risk for HIV transmission from their personal, rather than their professional, behaviors. [50] One study in Australia showed that gay men are also more

likely to forego condom use with trusted partners than during casual sexual encounters. [51] Alcohol use is also associated with failure to use condoms. [52]

Even talking about AIDS to a prospective sexual partner can be difficult, as one study of heterosexual college students demonstrated. Sheryl Perlmutter-Brown and Paula Michal-Johnson of Villanova University surveyed 243 students in public speaking classes. Just over half (56 percent) of the students reported talking about AIDS in a relationship; women were more likely than men to report talking about AIDS. Although more than half of the students reported that AIDS had changed the way they date, the vast majority who did talk about the disease did so in ways that did not challenge their relationships -- making jokes, talking about other people, or discussing news events. The researchers report that "Talk, not real communication, characterizes most of the AIDS talk analyzed so far. Few partners are talking seriously, at length or in any depth, about their feelings, attitudes, risk factors, or fears about AIDS." [53]

Educational efforts aimed at adolescents must overcome all these impediments, in addition to the particular difficulties associated with this developmental stage. Adolescents are at particular risk, according to Karen Hein, M.D., Director of the Adolescent AIDS Program at Montefiore Medical Center in the Bronx, because of "prevailing patterns of adolescent sexual activity, the age of initiation of first intercourse, current contraceptive practices [i.e., failure to use contraception], the choice of sexual partners, rates of venereal diseases, and anatomic and physiologic considerations. [54] Risk is not distributed equally; those at particular risk include homeless youth, runaways, prostitutes, gay youth, teenage sex partners of homosexual or bisexual men or of drug users, and adolescents who live in areas of high HIV seroprevalence. [55]

Many adolescents have incorrect information about modes of transmission, although their knowledge gaps generally concern ways the virus is <u>not</u> transmitted rather than ways in which it is. The Centers for Disease Control surveyed samples of students in grades 9 to 12 in six cities (including New York City) and nine states (including New Jersey). Although a high percentage (83.8 percent to 98.1 percent) knew that HIV could be transmitted through drug use and sexual intercourse, many incorrectly thought that HIV infection can be acquired from giving blood, using a public toilet, having a blood test or from mosquito bites. Other studies have shown that black and Hispanic adolescents, at greater risk because of the higher prevalence of HIV in their communities, are also more likely to have misconceptions about transmission than white students. [56]

The high school students were also asked to report on their drug use and sexual behavior: 2.8 percent to 6.3 percent reported injecting cocaine, heroin, or other illegal

drugs, and 28.6 percent to 76.4 percent reported having had sexual intercourse at least once. At each site, more male than female students and more older than younger students reported these behaviors. [57]

A study of adolescents and young adults in Newark, New Jersey, showed both high levels of AIDS knowledge and high levels of risky behavior. The 73 subjects correctly responded to over 80 percent of the questions on a standard AIDS questionnaire. Yet only 23 subjects were not sexually active; those who were active started between the ages of 12 and 14. Of the sexually active subjects, 27 admitted to drug use, while only four of the non-sexually active subjects used drugs. More than two-thirds of the sexually active subjects reported that they did not use condoms with partners whose sexual history was unknown. The authors concluded that "additional passive educational programs focused in increasing AIDS awareness and AIDS-specific knowledge are unlikely to substantially reduce sex-risk behaviors in sexually active adolescents." As an alternative, they propose individualized interventions designed around the subject's specific risk behaviors. [58]

A study of knowledge, attitudes, beliefs, and behaviors in a New York City adolescent minority population showed that sexual activity was the major risk factor, with 58 percent reporting having engaged in sexual intercourse and 12 percent of these having never used contraception. Despite generally good knowledge about modes of transmission of HIV, over half believed that a person who donated blood could become infected with HIV and 47 percent "never" or "rarely" worried about the disease. Of the total group, 39 percent reported behavior changes; of these, 66 percent (25 percent of the total group) reported using condoms currently and 16 percent (6 percent of the total group) said that they were abstinent. Twenty-one percent volunteered that they would commit suicide if they had positive test results. Although such a statement certainly cannot be taken at face value, it reveals the deep level of stress and anxiety associated with confronting the possibility of one's own vulnerability. [59]

Knowledge levels among adolescents with hemophilia, a group with an HIV antibody-positive rate of 70 to 90 percent, are high; nevertheless, participants in one study "frequently behaved in ways that were potentially harmful to themselves and others." Specifically, sexually active young men, although aware of the importance of using condoms, were not practicing safe sex. Not all had disclosed their hemophilia (or, presumably, their HIV status) to sexual partners. Moreover, 42 percent of the subjects reported that they did not believe that the heat-treated clotting factor derived from pooled blood plasma, which is necessary for treatment of their disease, was safe, despite repeated assurances from doctors. As a result, they restricted the use of this product to episodes of known or suspected bleeding. Despite their HIV serostatus and the high likelihood of progressing to serious illness, participants

estimated their own chances of getting AIDS at from 0 to 50 percent, with a mean of 13 percent. They expressed considerably more concern about doing well at school, disagreements with their parents, and being attractive to the opposite sex -- in other words, the typical concerns of teenagers. [60]

Barriers to effective AIDS education among teenagers relate to a set of nearly universal characteristics: minimal knowledge of contraception, inexperience with negotiating contraception with a partner, fear of rejection, the importance of peers as a reference group for information and behavioral norms, unsettled sexual self-concept, concrete thinking and short-term orientation, denial of danger, interest in experimentation and risk-taking, alienation from family and public institutions, and low sense of personal efficacy. [61] Mary Beth Sunenblick, a social worker, concludes: "As adolescents are exploring their sexuality, they must come to terms with the reality of AIDS, particularly the potentially fatal outcome of the disease. They are asked to face their mortality at a time when their feelings of immortality and invincibility are at their highest." [62] "All teenagers want to have safe sex just like they want to have good grades," says Alex Jones, a teenage peer counselor in San Francisco. "They just don't want to do what's necessary to get it."

There are a few signs that behavior is changing. The 1988 National Survey of Adolescent Males, conducted by the Institute for Survey Research at Temple University, found a surprisingly high level of condom use compared with 1979 levels. Among 17- to 19-year-olds living in metropolitan areas, condom use at last intercourse more than doubled -- from 21 percent to 58 percent. The young men in the survey -- 60 percent of whom are sexually active -- had high levels of knowledge about HIV and how it is transmitted, and did not think that using condoms was too much trouble to prevent disease. However, the rates of condom use were significantly lower than average among young men who had ever used IV drugs or whose partners had done so, young men who have had sex with a prostitute, and those who have had five sexual partners or more in the past year. These results suggest that condom use is catching on, but not in the group that engages in the riskiest behavior. [63]

To sum up, the most serious barriers to effective education -- that is, education that results in sustained behavior change -- arise from characteristics of groups and individuals, the intimacy of the behaviors in question, the ambiguity of some educational messages, and the difficulty in translating knowledge into behavior change.

7. Developmentally appropriate school-based AIDS education should be supported from kindergarten through higher education.

Studies show that most parents want their children to learn about AIDS and they want the schools to play a major role in that education. In their focus groups described earlier the Public Agenda Foundation found virtual unanimity on the question of providing explicit information about AIDS and its transmission to junior high and high school age students. A Dallas area woman said, "Ideally, kids would get information [about safer sex] from their parents. But parents don't always take the time to talk to their kids. Or maybe they're uncomfortable. Or maybe they don't know." Parents were more divided about whether educational information should stress abstinence while also providing information about how to avoid AIDS. [64]

A majority of parents talk to their children about AIDS. The NHIS survey report for January-March 1989 indicated that 63 percent of parents with children aged 10 to 17 years have discussed AIDS with them, and 60 percent say that their children have received AIDS education in school. [65] A smaller percentage of Hispanic parents (48 percent) report having discussed AIDS with their children,[66] but the percentage of black parents was the same as whites. [67]

Virtually every large school district and all but four states support AIDS education, and nearly as many districts provide instruction about sexually transmitted diseases and abstinence. Fewer states and districts require or encourage schools to teach about pregnancy prevention. AIDS education is receiving more funding and attention from both states and local school districts than is sex education. [68]

Nonetheless sex or AIDS education, however circumscribed or limited, is now the norm in high schools all over the country. Ninety-three percent of public school teachers in grades 7-12 in five specialties -- biology, health education, home economics, physical education and school nursing -- report that their schools offer sex education or AIDS education in some form. These teachers regard pressure or potential pressure from parents, the community, or school administrators as their major problem, although they also cite lack of appropriate materials on the subject, and students' reactions (embarrassment or lack of basic knowledge of anatomy and physiology) or attitudes (apathy, lack of values or morals, or favorable attitudes toward teenage pregnancy). [69] The teachers' perception of a lack of parental support is not borne out by public opinion polls, which indicate strong support among parents for sex education. [70] Some of this discrepancy may result from controversies over specific topics (birth control, "safer sex," homosexuality) rather than disagreement in principle. Some may also be a result of anticipated parental objections, rather than actual protest. Finally, a minority of very determined parents who object to sex or AIDS education may be perceived as having more support than they actually do.

The most controversial aspect of AIDS education in the schools is not whether it should be taught, or by whom, but what the message should be. One view is that abstinence should be the only message, and that any instruction on alternative methods of prevention will encourage and sanction sexual activity, which should be discouraged. Moreover, this argument continues, condoms are not 100 percent effective in preventing pregnancy, and therefore will not be completely effective in preventing HIV transmission because sexually inexperienced adolescents are particularly likely to use condoms ineffectively. Therefore, the message that condoms are "safe" gives young people a false sense of security. This view is represented in the Archdiocese of New York's AIDS curriculum, which follows the New York State Department of Education curriculum in major respects but does not include instruction on condoms. Interestingly, in the national study of state AIDS curricula, the authors found the New York State curriculum to be among the most critical of all prevention measures except abstinence. New York is also the only state to highlight the negative aspects of birth control, listing "freedom from the bother and dangers of the pill, IUD and other contraceptives" as one of the advantages of abstinence. [71]

Considering the realities of both politics and adolescent sexual behavior, most official guidelines tread a nervous line between stressing abstinence and presenting alternatives. The Centers for Disease Control's guidelines for effective school health education encourage school systems to make programs available that will enable young people who have not engaged in sexual intercourse to "abstain. . . until they are ready to establish a mutually monogamous relationship within the context of marriage." Young people who are having sex are to be encouraged to stop until they are ready for marriage. "Despite all efforts," the CDC concedes, "some young people may remain unwilling to adopt behavior that would virtually eliminate their risk of becoming infected." Therefore, it recommends that "school systems, in consultation with parents and health officials, should provide AIDS education that address preventive types of behavior." These include condom use. [72]

The American Academy of Pediatrics' Committee on School Health's recommendations, while similar in content, are more pragmatic in tone. It recommended in August 1988 that "the nation's schools should immediately initiate AIDS education programs as part of a comprehensive health education plan." This education, according to the Academy, should begin in kindergarten and continue through 12th grade, with instruction appropriate to the age and development of the students. In terms of prevention, the Academy recommends that abstinence be presented as the safest method of prevention. However, the Academy continues:

> Because not all students will remain abstinent or be able to ensure that their sexual partners are uninfected, appropriate barrier methods should be discussed as part of the curriculum. The proper use of latex condoms and virucidal spermicides

> (contraceptive vaginal foams containing nonoxynol 9) should be described, as well as the lack of protection against AIDS from use of oral contraceptives alone. [73]

The view that discussion of condoms will promote sexual activity is not borne out by data. A comparison of the United States with Canada, England, Wales, Belgium, and Sweden -- all countries with more sex education, readily available condoms, and condom advertising -- showed that teenagers in the United States have higher pregnancy and abortion rates. [74] However, it would be unrealistic to assume that simply including information on condoms in AIDS education will result in a dramatic increase in their use. A review of five studies conducted from 1980 to 1987 in the United States showed that sex education has little or no effect on altering sexual activity, promoting the use of birth control, or lowering teenage pregnancy rates. The authors -- Drs. James W. Stout, of Children's Hospital and Medical Center, and Frederick P. Rivara, of Harborview Medical Center in Seattle, Washington -- point out that

> The reasons for the increase in teenage pregnancy and increasingly early age at initiation of sexual activity are complex and are rooted in the changing values of our society and the subcultures within it. School courses may improve knowledge concerning reproductive health and contraception [and AIDS prevention]. However, the existing data suggest that a classroom course alone cannot be expected to change sexual behavior in a direction that is in opposition to the adolescent's sexual world as molded by the television, motion picture, music and advertising industries, as well as peer group and adult role models. [75]

As already noted, New York State has developed a curriculum for AIDS education in grades K-12. The New York City Board of Education and the Archdiocese of New York City have curricula as well. With funding from the Centers for Disease Control, community school districts have been trained in the "Kids on the Block" program, which uses life-size puppets in grades 4 through 6. New York City has a citywide AIDS Advisory Committee. Considerable controversy surrounded the use of the film "Sex, AIDS, and Drugs," commissioned by the New York City the Board of Education; a modified version was eventually approved for use.

In July 1989 the New York City AIDS Task Force recommended that:

> All children in grades K-12 should be provided with age appropriate comprehensive health education which focuses on AIDS issues. The Board of Education must give priority to hiring AIDS staff to provide increased and accelerated staff development, parent leadership, peer leadership, and resource people for technical assistance and monitoring. [76]

The Task Force also recommended that the Board of Education expand drug treatment and education programs to cover grades K-12, with grades 4-6 receiving priority.

The New Jersey Departments of Health and Education have developed instructional guides for teachers in grades 6 through 8 and 9 through 12. The New Jersey Department of Education surveyed the state's school districts in December 1987 and found that 69 percent of the reporting districts (486 or 81 percent of the total) provide AIDS instruction, and 21 percent have involved parents and/or other appropriate community members in the development of their AIDS program. Preliminary data from the 1988 survey show a higher response rate (94 percent). Therefore only 1 percent of the state's students in grades 7 through 12 are not receiving any AIDS education. [77]

According to the 1987 survey, the amount of classroom instruction ranged from an average of two hours per year for grades K through 5, four hours per year for grades 6 through 9, five hours in grade 10, and four hours for grades 11 and 12. AIDS instruction was provided in health classes in 59 percent of the districts, and in 48 percent of family life classes, with some overlap, because some districts provide instruction in both. Seventy-five districts provided AIDS instruction in science classes, 20 in home economics classes, 25 in social studies classes, and 36 in special assemblies.

In terms of program characteristics, 50 percent of the New Jersey school districts described abstinence as the only sure way to avoid AIDS infection, 62 percent described specific risky behaviors, and 48 percent included information on condoms as a way to reduce risk.

But a curriculum is only the beginning. Staff training is an immediate and pressing need in all jurisdictions. Although AIDS education is widespread, there is as yet no evaluation and no quality control. Teachers need special training to prepare themselves for dealing with a topic that is as sensitive for them as it is for their students. They need thorough grounding in the facts of AIDS and advice on how to handle the emotions and questions that may arise. Much of the funding for AIDS education has come from CDC grants and, in New York, from the state AIDS Institute; a commitment to continue and expand AIDS education at the local level must also include local funding.

Special efforts must also be made to reach youngsters who have dropped out of school, and who are at higher risk of the behaviors that transmit HIV. These teenagers need to be educated in nontraditional ways if they are to understand their risks and take measures to prevent HIV infection. [78]

In sum, with a large measure of parental support, educational institutions have begun to meet the challenge of educating young people of all ages about AIDS. However, serious divisions of opinion about the content of the educational message remain. For the future, educational institutions must go beyond curriculum development to staff training and parental involvement to ensure that the educational efforts are effective. Adequate funding for these efforts is essential. Special efforts must be made to reach young people who are not enrolled in school; their isolation from traditional institutions makes that task formidable but especially important.

8. Educational programs should be evaluated for their effectiveness.

Evaluation is one of the weakest links in the chain of education services, but it is essential for the development and funding of future programs. Early education programs lacked rigorous research design. That is not surprising, as Jane E. Sisk and her colleagues at the Congressional Office of Technology Assessment point out:

> Faced with a new and usually fatal disease, the immediate concern of organizations funding programs and public health workers implementing them was to curtail the spread of HIV infection. As a result, however, knowledge about the effectiveness of particular programs and of specific elements of programs has accumulated slowly. [79]

Evaluating of the outcome of educational interventions in general, and of AIDS education in particular, is complicated for several reasons: the difficulty in establishing which intervention, if any, makes a difference; the difficulty in determining the effect of other messages in the background (e.g., the media, peer pressure); the problem of establishing controls where it is unethical to withhold prevention information from one group; the problem of generalizing from the studied group to others; rapidly changing social norms; the difficulty in following-up reported behavior change; and the problems of assessing any self-reported behavior change. [80] Foundations that have funded AIDS education programs often do not have the expertise to design or execute an evaluation; the organizations they fund also tend to be less sophisticated in this area. In addition, evaluations are expensive and time-consuming and they divert resources from service provision. [81]

However, some basic evaluation efforts of most educational programs can be undertaken with relative ease. Dr. David G. Ostrow, director of the Midwest AIDS Biobehavioral Research Center, suggests the following evaluation criteria:

- Is the information simple, unambiguous, and presented in a culturally sensitive fashion?

- Are the behaviors to be modified specifically addressed?
- Are substitute behaviors, pleasures, and social activities presented?
- Are the substitute behaviors portrayed as being supported by the community? Does the message promote their widespread acceptance?
- Are cultural, ethnic, economic, and geographic barriers to behavior change recognized and resources for overcoming them provided?
- Are norms and values that sanction continued high-risk sexual or drug-use behaviors critically scrutinized and constructive alternatives given?
- Is there follow-up to ensure that appropriate behavior changes has been adopted, assess potential negative consequences, and reinforce continuance or completion of appropriate behavior change? [82]

In New York City, the Health Services Improvement Fund (HSIF), a foundation sponsored by Blue Cross and Blue Shield, has launched a project to assist five community-based organizations providing HIV prevention services in evaluating the effectiveness of their efforts. HSIF will provide funding and the assistance of a professional researcher to enable its grantees to develop and carry out evaluations. The Foundation will also identify particularly successful interventions or strategies that may be adapted by other organizations. The grants will be awarded in December 1989. [83]

To sum up, now that educational programs have been underway for some time, they should be evaluated in as rigorous a way as possible to ensure continued public support and to learn how to modify future programs. However, evaluation efforts face serious problems in this area as they do in all areas of human behavior. Evaluation should be used as a mechanism for improvement, not as a rationale for avoidance.

Summary and Recommendations

The following general principles should guide AIDS education and prevention programs:

1. **To be effective, educational efforts must contain several key elements:**

   a. Educational messages should be accurate, consistent, cumulative, and long-term.

   b. Educational messages should be communicated through all appropriate media and through numerous forms of one-to-one and small group contact.

   c. Educational messages should be developed by and communicated by persons who are knowledgeable, credible to the audience, and sensitive to the emotional and cultural nuances of the information.

   d. Effective educational messages may arouse a certain level of fear; however, other approaches, including positive alternatives to risky behavior, social acceptability, and humor, are often more effective.

   e. Education and prevention programs targeted at specific populations should be linked to the provision of appropriate services.

2. **Public education campaigns providing accurate, up-to-date, and clearly stated information about AIDS should be a continuing, coordinated, and high-priority effort.**

3. **The mass media have an important role to play in communicating basic information and in creating a social context in which targeted messages are more likely to be acceptable.**

4. **Targeted education campaigns for gay men should be continued and supported, so that those who have changed behavior can sustain those changes and those who have not can be motivated to change.**

5. **Drug users and their sexual partners are difficult populations to educate but they should not be considered "unreachable."**

6. Efforts to change risky behavior to prevent further transmission of HIV face significant barriers.

7. Developmentally appropriate school-based AIDS education should be supported from kindergarten through higher education.

8. Educational programs should be evaluated for their effectiveness.

Based on these principles and recognizing that no single sector of society can bring about all the needed changes and that all sectors working in their respective arenas will support one another's efforts the Citizens Commission on AIDS makes the following recommendations:

A. GOVERNMENT

Public health authorities at the federal, state, and local levels have a responsibility to provide AIDS education. After a shaky and uncertain start, in which education was largely and successfully funded and conducted by organizations in the gay community, governmental agencies such as the New york State AIDS institute, the New York City Department of Health, and the New Jersey State Department of Health, and the federal Center for Disease Control, have now committed more substantial resources and energies to education.

Based on the experience of the past nine years, the future role of public health agencies should be to:

1. **Continue to develop and fund general educational messages and programs.**

2. **Continue to fund community-based groups to develop their own targeted messages and programs.**

3. **Fund carefully designed social science research to learn more about (a) categories of individuals who engage in risky behavior but whose activities are largely hidden from society, such as bisexual men, and men of color who have sex with other men; (b) attitudes toward risk-taking, particularly among adolescents and those who continue to engage in risky behavior even after conventional educational efforts.**

4. **Stand firm against attempts to censor or restrict explicit information directed to specific groups such as gay men or drug users.**

5. **Establish AIDS Education Clearinghouses in New York and New Jersey, in collaboration with the private sector, to serve as resource centers for community-based organizations, service providers, the media, and the general public.**

B. MASS MEDIA

The mass media, when used appropriately, can raise public awareness and knowledge about basic AIDS facts. Further, it can create a climate in which people with AIDS are treated compassionately and those at risk are motivated to seek more specific information and counseling about risk reduction. A very large gap between public perception and scientific knowledge about risk remains. While advertising and news media have reduced that information gap, particularly among better educated people, more needs to be done.

Advertising campaigns have been limited in effectiveness because their messages are inconsistent and apparently contradictory (for example, one message says that AIDS is hard to catch while another says that everyone is at risk). In addition, the messages appear for short durations, in time slots with limited audiences, and without the intensity of repetition that is essential for impact.

1. **AIDS prevention messages should be approached as a marketing problem: the expertise of the advertising and marketing community should be marshaled to contribute to this goal with the same energy and resources they would devote to selling a commercial product.**

2. **Local media outlets should work together to develop a comprehensive plan for presenting AIDS prevention messages to their audiences. The first step should be an inventory of what has already been presented to determine content, frequency, and intended audiences. The next step should be a focused discussion with AIDS prevention specialists to outline the major elements of an effective campaign. Finally, a series of messages targeted to particular audiences through particular media should be constructed, and a marketing plan for disseminating these messages should be implemented.**

3. **In addition to public service advertising, television programming should include references to AIDS and HIV disease prevention as part of story lines in ways that are compatible with the characters and plot. That is, the episode need not be principally about AIDS in order to have an AIDS prevention message built into it.**

4. **Minority media should be particularly encouraged to develop targeted AIDS prevention messages and programming for their audiences.**

C. WORKPLACES

Except when promoting the health benefits of specific products, the corporate role in public health education has been limited. But the business community cannot afford to remain aloof from AIDS prevention: the health of its current and future workforces, and of their families and communities, as well as the added tax burdens that will inevitably accompany an expanded HIV epidemic, demand that it play a role.

1. **Businesses, in cooperation with unions where they exist, should provide HIV prevention education in their workplaces and encourage their employees to participate in community and school-based efforts.**

2. **Businesses can play an important role in AIDS prevention and education by providing financial support to the education efforts of national and community-based groups.**

3. **Businesses should provide HIV prevention education in their product inserts where it may be seen by individuals with no other access to AIDS education, such as low-income women. Examples are baby care and personal hygiene products.**

4. **Businesses that cater to minority markets (food producers, banks, and small neighborhood businesses) should support AIDS education for their customers.**

5. **Entrepreneurial efforts should be encouraged: one example is the development of novel ways to distribute condoms, promote their use, and make them more "user-friendly."**

D. EDUCATIONAL INSTITUTIONS

All institutions vested with the responsibility of educating young people -- public, private, and parochial schools, colleges and universities, and others -- should incorporate AIDS education into their programs. AIDS education should begin in kindergarten and continue through the 12th grade, with the most intense attention devoted to students in grades 7 through 12.

A scientifically accurate, developmentally appropriate curriculum is the first step. But a curriculum is only the beginning. Staff training is an immediate and pressing need in all jurisdictions. Teachers need special training to prepare themselves for dealing with a topic that is as sensitive for them as it is for their students. They also need thorough grounding in the facts of AIDS and advice on how to handle the emotions and questions that may arise.

1. **The New York City Board of Education should fund more aggressive attempts to train more staff in AIDS education, to introduce its curriculum citywide, and to evaluate the results.** While the Board has taken important first steps in these areas, the implementation of AIDS education still lags far behind the need.

2. **The New Jersey legislature should mandate AIDS education for students in grades K-12, and should provide adequate support to the New Jersey Department of Education to carry out that mandate. The Department of Education should work with local school districts to evaluate their AIDS instruction and to train staff in implementing their instruction guide.**

3. **Schools should take the lead in developing education programs aimed at parents.** Parents can benefit from AIDS education by learning what their children are learning and how to talk to them about the relationship among AIDS, sexual behavior, and drug use. Better-informed parents are likely to be more supportive of schools' efforts. An additional benefit is that many adults who engage in high-risk behavior may better appreciate their own risk.

4. **Colleges and universities in the New York-New Jersey area should provide AIDS education on a continuous basis.** AIDS education has been provided in many higher-education institutions; this should be continued and expanded, since new students enroll each year and others may need reinforcement to avoid high-risk behavior. The intensity of such efforts should not be diminished because of beliefs that a heterosexual epidemic is unlikely. While that may be so in terms of large populations, individual heterosexuals can be at high risk because of their behaviors. Moreover, most college populations include gay men at risk.

5. **Boards of Education should ensure that AIDS educational curricula and materials are appropriately developed and that instruction is provided in special and mainstreamed classes for students with visual, hearing, mental, and developmental disabilities.**

E. FOUNDATIONS

In recent years private foundations have begun to support AIDS education efforts to a greater extent, stimulated in part by groups like Funders Concerned about AIDS and the National AIDS Partnership's local groups in New York City and New Jersey. Private foundations should sustain and expand this involvement.

1. **Private foundations should place particular emphasis on programs that target hard-to-reach groups and that support efforts for which public funds are difficult to obtain.**

2. **Private foundations should fund innovative models and collaborative arrangements among groups with similar goals.**

3. **Private foundations should fund well-designed evaluation components or projects.**

4. **Private foundations should fund efforts to replicate or adapt successful models.**

F. COMMUNITIES

Communities, both large and small, are most effectively served by the sum of all these efforts by governments, mass media, businesses, unions, schools, and community-based groups. To determine whether a community is doing all it should for AIDS prevention, citizens can ask themselves the following questions:

1. **Do all the schools in the community have AIDS education programs? If so, what is the curriculum? How are the teachers trained? Is the curriculum accurate and up to date? Does it provide for referrals or follow-up sessions for those who need more specific advice? Do the schools have sessions for parents?**

2. **Do the major community-based organizations, such as religious organizations, youth groups, social groups, and others, provide AIDS education to their members? Are there ways for individuals at high risk to be referred for further counseling and health care services without violating their privacy?**

3. **Are families involved in AIDS education? Are there sources for support and referrals for families who want assistance in this area?**

4. **Does the public health agency support and fund community-based AIDS education? What is its target audience? What is its message?**

5. **Do the major businesses and unions in the community provide AIDS education in the workplace? Can this education be opened to others in the community?**

6. **Is anonymous or confidential counseling and HIV antibody testing readily available in the community?**

7. **Are the medical professionals in the community trained to deal with AIDS and HIV infection? Do they routinely discuss sexual behavior and drug use with their patients in a respectful and sensitive way? Do they share their expertise with the community through educational programs?**

8. **Do the media that reach the community present AIDS prevention messages that are appropriate for the audience?**

9. Does the local governmental body support educational programs and other interventions that may slow the spread of AIDS, such as support for drug treatment facilities?

10. Do local libraries have an up-to-date collection of audiovisual and written materials, in all appropriate languages and for all subgroups? Are there special materials for adolescents?

11. Are educational materials available in formats accessible to people with visual and hearing impairments? Are continuing, appropriately developed educational programs in place for people with mental retardation and other developmental disabilities?

12. Are there adequate drug treatment facilities in the community? Do drug treatment facilities provide AIDS education and counseling?

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Appendix: Profiles of Education Programs

Introduction

The following twelve profiles of educational programs and educators in New York City and New Jersey are a modest sampling of a burgeoning activity. As these profiles show, a variety of programs are reaching people with widely varying differences in culture, ethnicity, age, and life experience.

The profiles were written by Michael Rosen and Karyn Feiden and are based on interviews with program directors and information provided by the organizations. The Citizens Commission on AIDS has not formally evaluated these programs; they are included as evidence of the creativity and commitment of individuals and groups in the region to AIDS education.

All groups and individuals providing AIDS education face some obstacles in achieving their goals: inadequate funds, community or internal organizational resistance, denial of risk by their target audience, and many bureaucratic and social barriers. Nevertheless, each in his or her own way, these educators continue to pursue the same goal -- stemming the epidemic through education.

1. Association of Drug Abuse Prevention (ADAPT)
2. The Bilingual Learning Center of PS 121
3. Corrections AIDS Prevention Program (CAPP)
4. Gay Men's Health Crisis, Safer Sex Workshops
5. Harlem Week of Prayer
6. Health Services
7. Hyacinth Foundation, The Tupperware Party Model and Peer Education
8. Lavender Light Lesbian and Gay Gospel Choir
9. The Minority Task Force on AIDS
10. Planned Parenthood League of Middlesex County
11. Streetwork
12. Women's Center at Montefiore Hospital

Association of Drug Abuse Prevention (ADAPT)

In the shooting galleries frequented by IV drug users and along the streets strolled by prostitutes, the outreach workers of The Association of Drug Abuse Prevention and Treatment, Inc. (ADAPT) are working to prevent the spread of AIDS.

With funding primarily from the New York City Department of Health, ADAPT has been providing services to IV drug users since 1980, helping them enroll in drug treatment programs, advocating on their behalf and working to break down stereotypes about them. When AIDS hit the drug using population with such force the founders of ADAPT decided to expand their mission. They now work as aggressively to stop the spread of HIV as they do to get drug users into treatment. And they have broadened their outreach efforts in the five boroughs of New York City to include the sexual partners of IV drug users as well as addicted prostitutes.

ADAPT workers also set up tables on street corners and near bus stops in afflicted minority communities, where they disseminate literature and posters, distribute condoms, discuss safer sex techniques, and pass out packets containing bleach, water and cotton swabs used to clean needles and syringes. People who are not IV drug users or sexually active are also encouraged to take literature, condoms or bleach packages and to pass them along to someone who will use them. Workers read and discuss the contents of the brochures to those who cannot read English or Spanish. "The most important element in successful outreach is consistency. The community has to know you're there and will continue to be there, on the street, where they are, week after week," says Michael Bethea, Director of AIDS Outreach at ADAPT.

"Because we are known in the community we have access to the shooting galleries. The people who run the galleries know we are there to stop the spread of AIDS. For their own reasons they'll help us by including bleach and water in the packages of works they sell to the drug users and let us talk to the people there."

ADAPT outreach workers, many of whom have been recruited from drug treatment programs, also educate the community about AIDS through workshops and seminars at local therapeutic residences, at community centers, and in the public schools. "We use popular movies as an attendance draw in some settings. It is a good way to get people together and then once there, we'll educate them about AIDS. But the epidemic has gotten to the point where that is less and less necessary. We offer a workshop and people come. They want to know. The problems of attendance now center around issues like not being able to find someone to watch the kids, or not having car fare."

At their office on 111th Street in Manhattan ADAPT provides referrals for social, medical and legal services. Despite the long waiting lists at drug rehabilitation centers, the staff can often get drug users quickly enrolled in a treatment program. ADAPT also provides support groups for recovering substance abusers and for individuals infected with HIV. They have their own version of the buddy system, called the IV League Buddies, which enlists volunteers to provide companionship, support, and household assistance for recovering drug users with HIV disease. ADAPT also enlists help from doctors and lawyers who volunteer their time to provide free medical treatment and legal advice.

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The Bilingual Learning Center of PS 121

In the classrooms of the Bilingual Learning Center of PS 121 in Spanish Harlem, students are receiving age-appropriate AIDS education. Using the state curriculum on AIDS, Rosa Leon, the program's Science Mentor, works with other teachers to develop projects that both involve and educate the students. As their school science fair project last year's sixth grade class, #518, decided to survey their families, neighbors and community about AIDS. They had learned about HIV transmission in the classroom of teacher Miguel Martinez. With Martinez's guidance the students developed 10 questions to test knowledge and belief about AIDS. They spoke with 417 people and presented the following report, accompanied by AIDS educational materials collected from the local hospital. What follows is their report, verbatim:

"We of class 6-518 have undertaken as our project a somewhat limited but sincere survey of the fears, misconceptions, and realities of AIDS among Hispanics in el Barrio. We took it upon ourselves and interviewed 417 Hispanic persons in Spanish Harlem asking various questions.

"These are our findings:

1. 354 of the individuals interviewed did not know what AIDS was and what caused it.

2. 98% of the men interviewed were not at all concerned about AIDS -- all under 50.
3. All the women interviewed were somewhat concerned.
4. 87% of the women interviewed feared getting AIDS -- all under 45.
5. 38% of the men interviewed used condoms.
6. 21% of the women interviewed who engaged in sexual relations make sure their partners wore condoms.
7. 26 of the persons interviewed believed AIDS was a curse from God.
8. 47 believed in a cure - through herbs and prayer - 39 were women. 7 believed the body can heal itself - 5 were over 55.
9. 5 believed in destiny - all men.
10. 73% believed you can get AIDS from kissing, toilet seats, and sweat.
11. 28% believed donating blood can cause AIDS - 17 were men.
12. 94% believed that only male homosexuals and drug users can get AIDS.
13. 89% believed you can tell if a person has AIDS.
14. 102 persons believed there is not a cure and there will never be one.
15. 57 women and 13 men believed anal sex is the cause of AIDS.
16. 70% of the unmarried women interviewed would want their men tested before marriage.
17. 35% of the persons interviewed believed there is no prevention for AIDS.
18. All the Hispanics interviewed know and have read very little about AIDS.

"Through our findings we have concluded that our people need to be better educated about AIDS. Most of their fears are unfounded and superstitious. And we can't stress enough that our people need to be better educated about AIDS, so that they can be better protected.

"Thank you."

Their report won first prize at District 4's Science Fair. The class was visited by Richard Green, Chancellor of the New York City Board of Education; Robert F. Wagner, Jr., President of the New York City Board of Education; and Sandra Feldman, President of the New York City United Federation of Teachers. The students presented their findings to the School District Science Coordinators at the New York Academy of Science.

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Corrections AIDS Prevention Program (CAPP)

At least 35 percent of the prison population in New York City is HIV positive, according to official estimates. Yet the Corrections AIDS Prevention Program (CAPP), launched in 1987, was the first comprehensive program in the country targeted to prison inmates and correction officers and remains the only such project in New York City.

With such an alarming rate of infection, why has the prison population been so neglected? "Think of these words as I say them," advises Joyce Vowels, director of CAPP, by way of explanation. "Prison inmates, minorities, blacks, Hispanics, HIV and AIDS. What does that tell you? These people are the population no one wants to touch. They are transient, their education levels are low, they often fail to adhere to social amenities. And they don't go to PTA or to church."

As a result of the widespread negligence, ignorance behind prison walls is astonishing. "Fear takes hold here and intelligent people say things that make your mouth drop," says Vowels. She describes inmates who believed they were vulnerable to HIV simply because they were incarcerated and correction officers who thought themselves to be at risk for AIDS if they eat food cooked by homosexual inmates.

CAPP, run under the auspices of the New York City Department of Health, was designed to substitute facts for the myths that pervade behind bars. The key programmatic elements are preventive education, condom distribution, access to HIV counseling and testing, discharge planning and training for uniformed and civilian correctional staff. The staff that is assigned to cover 17 New York City correctional facilities make verbal and audiovisual presentations, lead group discussions that often include role playing and provide individual counseling.

Many CAPP staff members receive the first exposure to life behind bars during their training, an experience Vowels calls "mindblowing." Presentations are often made in front of the inmates' cells and staff members return to the home office in Manhattan stunned by the sight of so many young minority men in so much trouble. But Vowels also speaks optimistically about a shift in consciousness and a growing interest in the problems of the HIV-positive prison population. Other programs are being developed around the country and the prison population and their visitors have become much more open to CAPP's educational efforts. "At first, we were badgering the inmates and their visitors to come talk to us. Now, we can set up a table in the visiting area and people willingly approach," says Vowels. "Ironically, there is more fear now and that enhances receptivity."

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Gay Men's Health Crisis, Safer Sex Workshops

Gay Men's Health Crisis (GMHC) continues to be a pioneer in AIDS education. Since its inception in 1981, volunteers and staff have been developing innovative ways to help gay and bisexual men change their sexual behavior. Five years ago, the first of a series of safer sex workshops were launched. Here, gay and bisexual men receive detailed instruction on condom use, learn which sexual practices reduce the risk of transmitting HIV and discuss ways to negotiate safer sex with a partner. Extensive role playing, visualization and small group exercises are key components of these workshops. In 1987, GMHC published a facilitator's guide for the workshop "Eroticizing Safer Sex" allowing it to be easily replicated by agencies around the country.

Recently, a new workshop, called "Keep It Up," has been developed to help men sustain their commitment to safer sex. Participants grapple with the complicated emotional and social issues that earlier workshops could only touch upon. The program has been designed with the conviction that directly confronting sensitive subjects -- such as fear of rejection, loneliness, low self-esteem, lack of social support, and the awkwardness of condom use -- is the best long-term solution to preventing lapses into careless sexual behavior.

"For safer sex to be the norm, there needs to be a whole network of support," comments Michael DeMayo, assistant coordinator of AIDS prevention programs at GMHC. "The workshops are only one component of what GMHC does and what needs to be done. The safer sex message needs to be reinforced in a constant campaign that includes walk-in support groups, safer sex workshops, posters, a personal support system -- which means friends who believe in safer sex, too -- and constant reinforcement from society that the risk in unsafe sex is real and life-threatening."

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Harlem Week of Prayer

On Sunday, September 10, 1989 hundreds of people gathered in front of Harlem Hospital to launch a week of prayer to help heal the community and raise awareness about AIDS. There were religious leaders and community members from more than 75 religious congregations, speaking many different languages. There were the king, priests, priestesses and members of the traditional West African Yoruba religion. There were Baptists, Episcopalians, Catholics, Lutherans, Muslim Imams, Ethiopian Hebrews, the clan mother and medicine men and women of the Spiritual Way, a religion of Native Americans, and others. They all joined together to pray and educate their congregations about AIDS.

The unusual prayer vigil was the vision and determination of one woman -- Pernessa Seele, the Drug Addiction Project Administrator of the AIDS Initiative at Harlem Hospital. "I was getting ready for work one morning, thinking about how AIDS is devastating our community and how I was tired of reading about the non-responsiveness of the Black church and other religious organizations to this devastation. 'What can I do to begin to breakdown this resistance in the religious communities to AIDS?' The answer came immediately, PRAYER. I knew that prayer was the unique language of all religions and no religious organization would say no to praying for the healing of AIDS.

"When I began calling ministers, rabbis, imans, priests and priestesses, the overwhelming response was 'yes.' No one said no to this project. Many of the religious leaders wanted and needed leadership in dealing with AIDS in their congregation, and they desired someone from the community who knew and respected their beliefs and values. They felt comfortable with me because not only do I come from a very spiritual background, but I firmly believe in the power of prayer. Prayer Changes Things is my personal testimony. My spiritual consciousness and my understanding of the organizational structure of religions was felt and observed in my presentation of the idea. It was obvious to the religious leaders that the idea of a week of prayer was not a mere campaign, but a spiritual idea that I believed in. They could relate."

Out of those calls came an advisory committee with representatives from most of the religious faiths in the Harlem community, including Harlem Churches for Community Improvement, Harlem Valley Churches, the Council of Masajid, the Yoruba of North America, Inc., and the National Alliance of Native Americans. Community-based AIDS organizations, including the Upper Manhattan Task Force on AIDS, the Minority Task Force on AIDS, Inter-Council Community Fellowship, and the Family Health Project, were also represented on the advisory committee. The Week of Prayer was sponsored by the AIDS Initiative Program of Harlem Hospital

Center. The project was supported by such organizations as the Black Leadership Commission on AIDS, Council of Churches of the City of New York, Muslim World League, Catholic Area Clergy Conference of Harlem, and New York Theological Seminary.

During the week, prayer services and workshops were held in more than 50 congregations. The religious leader of the congregation selected one of ten AIDS-related topics, such as "Women and AIDS," "Drug use and AIDS," "Children and AIDS," etc. Each workshop began with basic information on HIV and how to prevent infection. The workshops were conducted by AIDS educators from Harlem Hospital, the New York City Department of Health and community-based organizations. The Week of Prayer concluded at Harlem Hospital Center with a Thanksgiving dinner and performances by Lavender Light Lesbian and Gay Gospel Choir and the Addicts Rehabilitation Choir. Over 100,000 Harlem residents became "AIDS Aware" through this outreach project.

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Health Services

Health Services, a non-profit agency in Jersey City, provides comprehensive reproductive health services to girls and women, regardless of their marital status or ability to pay. Like many other health-focused organizations, Health Services has expanded to include AIDS education for its client group. Other key services include pregnancy testing, counseling and termination; family planning services; and maternity and infant health services. Support groups are also available for pregnant teenagers and young parents.

One of the most exciting innovations is a teen pregnancy prevention group called "The Choice is Mine." In this once-a-week, after-school program, teenage girls and boys go on field trips, hear guest speakers, and to discuss sexual responsibility, life planning skills, abstinence, career choices, teen pregnancy, and decision-making skills. A group of teenagers between the ages of 12 and 20 have also created a theatre

group, under the auspices of Health Services, to address many of these same issues. The theatre group is funded by the New Jersey Department of Health and a grant from Health Mothers, Healthy Babies.

So far, these fledgling actors, none of whom has had previous theatrical training, have developed six skits lasting 20 to 30 minutes. "We try to address many of the awkward and complicated issues that surround teenage sexuality," says Joan Pollock, program assistant at Health Services. "It's not fair to expect teens to deal with the life-and-death issue of HIV and all the ramifications of teenage pregnancy without helping them acquire the skills necessary to negotiate safe sex or to say no. To only teach them what AIDS is and how HIV is transmitted isn't enough. Besides, it just won't work."

In one skit, a young man demonstrates how to put a condom on a banana -- it's humorous, but useful information gets passed along at the same time. In another skit, three girlfriends discuss safe sex and whether to encourage their boyfriends to use condoms. While sophisticated in talk and manner, the girls are naive and awkward about discussing condoms, until the leader of the group pulls one out of her pocket and teaches the other two how to unroll it.

One particularly moving skit features a young mother cradling her HIV-infected infant in her arms and wondering what will become of her child. The mother's husband, we learn, is a drug user who has left her. If she dies first, who will take care of the baby? If the baby dies first, how can she deal with her own pain and guilt?

Joan Pollock says that the objective of the skits is to help the audience imagine what being infected with HIV and being pregnant really means. "When you just talk about the issues, they are often not very real to people. When you show them a possible outcome, it gives them the opportunity to be more informed when they have to decide for themselves whether to have sex, and whether they will protect themselves."

The acting troupe receives eight weeks of intensive training to learn more about AIDS. Eventually, the performances will be structured to include greater interaction with the audience. The goal is to follow-up the skits with small-group discussions that allow audience members to ask questions and receive referrals for additional information.

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The Hyacinth Foundation, Tupperware Party Model and Peer Education

The Tupperware party model has been adapted by the New Jersey-based Hyacinth Foundation for use in AIDS education. In an effort to tap into the informal social networks of many communities, a host invites ten neighbors to her home, where trained volunteers make presentations about AIDS. To limit the burden placed on the host, Hyacinth volunteers do all the work, setting up ahead of time, providing all refreshments as well as paper cups and plates, and cleaning up afterwards. "We come and go and leave no trace that we were there except for a condom or two, " says JeanneMarie Mirabella, the Foundation's director of special projects. The model was developed with a grant from the Union Foundation and is being continued with a grant from the Metropolitan Life Foundation

The goal, says Mirabella, is to help people understand the reality of AIDS and HIV infection, the invisibility of the infection and the skills necessary to avoid it. The parties were first held in Union County and have been extended to Newark; several have been run in Spanish. "When we begin, people wonder why we are there, they think they know everything they need to know," says Mirabella. "By the time we leave, they thank us for coming and usually say, 'My friend, my son, or my sister really needs to hear this.'"

Volunteers find that it is impossible to separate complex and personal issues about relationships from concerns about AIDS. Asking someone to wear a condom -- and being prepared to turn down his sexual advances if he says no -- can feel particularly threatening if a woman's sense of self-worth is closely tied to having a man in her life. "Some women are making a tradeoff -- they want to feel safe tonight so they are not thinking about their long-term safety," observes Mirabella.

Many of the questions that arise at the home parties are phrased "I have a friend who..." One example: "I have a friend who has sex with a lot of different men. There's only one who won't use a condom. What's her risk?" Participants don't always like the answers they get but they do leave the evening session with some serious misconceptions dispelled.

The premise of peer education is straightforward: "Kids listen to each other much more than they would listen to me," says Mirabella. While the value of peer education has already been demonstrated nationwide, Hyacinth is the first to use it in the classroom to teach students about AIDS.

Some 100 peer educators are currently being trained in six New Jersey elementary and high schools. In recruiting educators, a concerted effort is made to bring a cross-section of students into the program. "If you have only wild kids, or

smart kids, or jocks, then the only people they are going to be able to reach are the ones who are just like them," says Mirabella. Much more effective is a mix of personalities and a balance between boys and girls, an ideal that is very hard to achieve because girls volunteer more readily than boys. Because of the correlation between age and social status, it has also proven most effective to have children going into the classroom of students who are a year or two younger.

Overcoming resistance within the school district was the first challenge to the successful introduction of the AIDS education program. When Hyacinth first developed the idea, Mirabella sent letters to more than 450 principals, 90 substance abuse counselors, and scores of other professionals working within the school districts. The program, she wrote, was available without charge and could be tailored to meet whatever needs the schools have. The response to her open-ended offer? Eight expressions of interest.

Parents sometimes raise a fuss when they learn that AIDS education is being offered in their schools, especially when outsiders are involved. Their concerns are genuine, says Mirabella, who often uses the following analogy to win converts to the value of the program: "I don't advocate crime but I acknowledge there are people who will rob me and I lock my doors. And I would prefer that fourth graders not be having sex. But we have to acknowledge that kids do have sex whether we like it or not, and we have to take steps to protect them."

Hyacinth has received a grant from the AT&T Foundation to train minority adults to work as volunteers in outreach programs targeted at minority youth and women.

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Lavender Light Lesbian and Gay Gospel Choir

In a world where being Black, being gay, and being part of organized religion have largely been socially exclusive, Chas Bennett Brack , Lidell Jackson and Tony Teal have created Lavender Light: The Black and People of all Colors Lesbian and Gay Gospel Choir. "We are a choir to keep alive a Black gospel music tradition in

an environment supportive of lesbian and gay people," says Chas Bennett Brack. "You are pushed to choose between one of the two communities but there's no real reason to choose. We don't want to leave our culture to become gay."

Their decision to address AIDS during their performances came out of the same kind of thinking. Brack says: "We were sitting around talking about how a lot of the Black churches haven't picked up on the idea that AIDS is in our community. And since so much of our political organizational stuff has happened in the church, why not this? It is a very political issue. It affects us both as gay people and Black people."

In some concerts their AIDS message is very short. At some point in the program someone will announce: "There is good news about AIDS and that is what we want to share with you tonight. The good news about AIDS is that if you are infected with HIV you don't need to infect someone else. If you aren't infected with HIV you don't need to become infected." It's a simple message, but it's as heartfelt and moving as the performance surrounding it. A more extensive AIDS education message, in the form of a journal, is included in the seven performances funded by the U.S. Conference of Mayors. Before the performance a guest speaker discusses how HIV is transmitted, how people can protect themselves against infection, and that AIDS has no color.

The Lavender Light audience has come to hear gospel music, not to be lectured about AIDS. By incorporating a message about HIV disease into their program, the choir says, in essence: We can't ignore this, and we don't think you should either. HIV disease is a fact of life, not a special event to be relegated to a separate forum.

Lavender Light also provides another special and equally important role in humanizing the AIDS epidemic. Brack says: "People with AIDS were coming up to us and saying they felt better after they came to one of our concerts. There is no greater endorsement than to have one individual with AIDS say, 'You made me feel better.' To stop someone's suffering for five minutes in the face of this epidemic is a job well-done, and we take it very seriously. That's the reason we can't be just a gospel group that just entertains."

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The Minority Task Force on AIDS

The Minority Task Force on AIDS, initially an offshoot of the New York Council of Churches, has been incorporated as an independent agency since early 1988. Its mandate is to provide direct services -- including counseling, educational programs, social activities, and soon, a buddy program, legal services, and supportive housing -- to HIV-infected persons in upper Manhattan, particularly the central and East Harlem neighborhoods. "I take seriously our mandate to serve people of color," says executive director Ronald Johnson, whose constituency currently includes mostly Black and Hispanic individuals.

Under contract with the New York City Department of Health, the Minority Task Force on AIDS has run home focus groups for more than 1,500 individuals during the past year. Guided by a trained facilitator, a group of 10 to 20 men meet in a relaxed social environment at a volunteer's home to talk in frank and personal terms about safer sex -- what it is, why it is important, and how to negotiate for it with a sexual partner. "The essence of our message is that safe sex is something you have to practice all the time," says Johnson.

Asked whether the message about safer sex has penetrated the minority community, Johnson observes that people understand the concept, but "when pressed to define it operationally, they show serious gaps in knowledge." And the rationales for failing to practice it ar extraordinary. Some examples: "I don't have sex with white guys so I don't have anything to worry about." "The man I am having sex with is not a drug user so there's no problem." "He looks clean." "We've been going out together for a week or so we're a couple now." "I'll do it if the other guy does it."

In addition to the home focus groups, which are intended as a one-time training, the task force runs ongoing support groups. Here, efforts are made to cement earlier lessons about safer sex. "The message is, 'Okay, now we know what safe sex is, now what are the psychological hangups that might prevent us from practicing it?'" explains Johnson. Task Force outreach workers also operate aggressively in the community, going into bars and cruising areas to talk about safer sex with patrons.

One outreach worker is assigned to focus mostly on IV drug users but Johnson is disturbed by the myth that this is the only group in the minority community vulnerable to HIV infection. "If there is one fallacy I wish I could banish, it is that all gay men with AIDS are white and all IV drug users with AIDS are black and Hispanic," said Johnson, citing statistics that show roughly half the minority population infected with HIV acquired the virus through sexual contact. A key objective of the AIDS Minority Task Force's education efforts is to dispel that myth.

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Planned Parenthood League of Middlesex County

Planned Parenthood League of Middlesex County has been in the field of public health education since long before the AIDS epidemic. For 19 years it has provided seminars, outreach and counseling on reproductive health issues; the extension into AIDS education came out of client demand and recognition of their community responsibilities. Ellen Koteen, the Executive Director, said "People from organizations that we provided our services to long before came to me and said, 'We need help with AIDS.' So we trained our staff and began providing seminars and counseling. In 1987, we received a special state grant to conduct AIDS community education programs."

About one third of the agency's 250 annual presentations are on AIDS. Their trained health educators speak to civic groups, synagogue and church congregations, college and high school students, and local prison inmates. They have also prepared special programs for the developmentally disabled, a population usually overlooked in AIDS education. "The developmentally disabled get very little attention historically. People think if you're disabled, you don't have sex. It's just not true. There is also a lot of denial of sexual activity, among the parents of disabled young adults."

The AIDS presentations are tailored to the particular needs of the audience, run from 40 minutes to 3 hours, and are usually quite informal, with much of the time devoted to questions and answers. Written materials reinforce the message and videos are used as well. Ellen Koteen recognizes that one-time presentations are unlikely to change behavior. She said: "The most striking thing about these presentations is the broad range of participant knowledge. In our presentations in high schools, some students will have a sophisticated understanding of HIV transmission and others will admit to being afraid to sit in a chair that someone with AIDS just sat in. Our goal is to get the information out there. The agency has developed eight week programs for junior and senior high school students with the goal of decreasing the high risk behavior of participants."

In cooperation with two other groups, Women Aware and the New Jersey Association on Correction, the Planned Parenthood League of Middlesex County will launch a pilot project beginning in January 1990. Funded by a special grant from the United Way of Central New Jersey, two part-time community workers will provide outreach to women in Middlesex County who are at risk for HIV infection and who are not involved in social services or community activities that provide access to AIDS information. The outreach workers will go to laundromats, welfare waiting rooms, prison waiting rooms, housing projects, and food stores to offer information and referral services. Says Koteen: "Women are typically the last to come in for medical treatment. They've had poor access to the services and have always taken

care of their children and husband before themselves. This program will attempt outreach to women who probably haven't been educated about AIDS through the usual channels. What shocks people in New Jersey most is that we have the highest percentage of women with AIDS in the country. And in one hospital in Newark, their life expectancy is 15 weeks from diagnosis to death, far shorter than for men. A critical need right now is for medical research to further identify the differences in how HIV disease is manifested in women as compared to men so that women can be diagnosed far earlier."

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Streetwork

Streetwork offers counseling and intervention services for homeless youths between the ages of 13 and 19, funded by the New York State AIDS Institute, the New York City Department of Health, and the City's Bureau of Special Services for Children. Through their outreach workers and word-of-mouth on the street, teenagers arrive at their storefront office in Manhattan for everything from a place to shower to the chance to participate in a support group on negotiating safer sex. Counselors work to find them housing, food, clothing, medical treatment, drug rehabilitation services, and psychological services. Sometimes they also escort them to appointments. In short, Streetwork is a home, or at least a home base for many of the homeless youths in that neighborhood. Like parents who display their children's painting on their refrigerator door, Streetwork counselors proudly hang pictures drawn by their young clients on their office walls.

But the work with these youngsters takes place as much on the street as in the office. Information about how HIV is transmitted is discussed in informal street meetings between outreach workers and groups of runaways. Recognizing that drug use and prostitution are day-to-day realities for many of these youths, AIDS discussions are very practical: kids are taught how to say "no" to johns who won't use condoms and how to clean works if they shoot drugs. Condoms are typically distributed during these street sessions.

Streetwork also has a more formalized AIDS prevention program. Jim Bolas, the AIDS coordinator and Stacey Rubin, an outreach worker, lead 12 workshops on a wide variety of HIV-related issues of concern to the youths. Topics include developing a positive body image and taking care of one's health, negotiating safer sex, dealing with feelings about death, and coping with AIDS-related prejudice. In addition, AIDS co-coordinator Paula Santiago runs a weekly recreation group for HIV-positive youths.

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Women's Center at Montefiore Hospital

At the Women's Center at Montefiore Hospital, in the southwest Bronx, 20 HIV-positive men and women gather weekly to provide practical and emotional support to one another. All of the participants are ex-drug users and each one is struggling with the terrifying specter of grave illness. The issues they explore are powerful indeed: How do I live with the thought of dying? What do I tell my family? What will become of my children? Once a month, parents, children, and other family members, all struggling with their own fears and sorrows, participate in the sessions.

The Women's Center, founded in 1987, opened with a largely academic mandate: to research the spread of AIDS into the female population. Today, a combination of corporate, foundation and public funds have enabled it to expand into the realm of active intervention and education. Along with the HIV-positive group, other support programs are available, including ones for current and former drug users and for pregnant women who have tested positive for cocaine.

The HIV-positive group was originally targeted at women only, but its mission has been broadened at the behest of participants. Professional facilitators help keep dialogue moving -- project director Kathleen Eric is a nurse with Master's degrees in public health and education, and two anthropologists and several psychology students are also involved. But the emphasis is on peer counseling. "It is really community people helping other community people and that's why it works," says Eric.

While most programs for drug-using populations focus on confrontation, the Women's Center model is geared towards education and support. Often, psychodramas allow participants to act out particularly emotional situations. Recently, an HIV-positive woman and her partner reenacted the tense moment when she revealed her antibody status, after having left him in the dark during the first ten months of their relationship. An all-too-common situation, it proved an important opportunity for group members to observe, identify and share their feelings about the issues being raised.

Proof that these techniques are working, according to Eric, comes from recruitment and retention figures. "No one thought this group of people would stay in the program, but they are coming together every week." Eric also points out that "as people begin to relate to each other and to help each other, the group itself acts as a therapeutic agent."

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Acknowledgments

The Citizens Commission on AIDS acknowledges with gratitude the assistance of all the many AIDS educators and community leaders who contributed in significant ways to the Commission's understanding of the issues in prevention and education of HIV infection.

Speakers at Commission meetings or seminars were Karen Hein, M.D., Director, Adolescent AIDS Program, Department of Pediatrics, Montefiore Medical Center; Charles McKinney, Ph.D., currently Director, Center for AIDS Education, University of Medicine and Dentistry of New Jersey; Harold Levine, CEO of Levine, Huntley, Schmidt & Beaver; Milton Gossett, President of Saatchi & Saatchi; Steven Rabin, Senior Vice President of Ogilvy & Mather; Allan Brandt, Assistant Professor of the History of Medicine at Harvard University; Bishop Edward Egan, formerly Vicar for Education of the Archdiocese of New York: Robert Johnson, M.D., specialist in adolescent medicine at the New Jersey Medical College; Edward T. Lalor, Director of the Division for Program Development of the New York State Department of Education; Eleanor Singer, Ph.D., the Center for Social Sciences, Columbia University; Theresa Rogers, Ph.D., the Center for Social Sciences, Columbia University; James Kinsella, Editorial Page Editor Los Angeles Herald Examiner and a 1988 Fellow at the Gannett Center for Journalism Studies at Columbia University; Daniel Fox, Professor of Humanities and Medicine, SUNY-Stony Brook; Dorothy Nelkin, Clare Booth Luce Visiting Professor of Sociology, New York University; Karolynn Siegel, Ph.D., Director of Social Work Research at Memorial Sloan-Kettering Cancer Center, Don Des Jarlais, Ph.D., formerly Coordinator of AIDS Research, New York State Division of Substance Abuse; Lawrence Brown, M.D., Director of Research, Addiction Research and Treatment Corporation of New York; Joyce Jackson, M.A., Community Outreach, AIDS Program, New Jersey Department of Health; Robert Newman, M.D., President of Beth Israel Medical Center, New York City; David Kanouse, Ph.D., Senior Behavioral Scientist, The RAND Corporation; and Michael Eriksen, Sc.D., Director of the Behavioral Research Program, The University of Texas System Cancer Center.

Others who met informally with Commission staff to share their experiences in AIDS education were Debra Haffner, Executive Director of the Sex Information and Education Council of the U.S. (SIECUS); Anita Mescouli, Community Resource

Exchange; Sylvia Schechter and Gerri Abelson, New York City Board of Education; and Anne Lindaman, New Jersey State Department of Education.

Many others provided important information and referrals, including Ellen Rautenberg, Assistant Commissioner, Division of AIDS Program Services, New York City Health Department; Jeffrey Lampl, Executive Director, Hyacinth Foundation; Doreleena A. Sammons, Director, Division of AIDS Prevention and Control, New Jersey Department of Health; and Valli Kanuha, Assistant Director of Education, Gay Men's Health Crisis. Kathe Karlson, Coordinator of Education and Outreach, and Sheila Lopez, Program Assistant, of the Upper Manhattan Task provided a very helpful overview of education programs in which the Task Force had participated.

The Commission also benefited from its participation in the Education and Prevention Work Group of the New York City AIDS Task Force, chaired by Megan McLaughlin of the Federation of Protestant Welfare Agencies and Ellen Rautenberg.

The following people read and commented on drafts of the report: David Kanouse, Senior Behaviorial Scientist, The Rand Corporation; Nancy Van DeVanter, R.N., M.P.H., director of the Columbia University Psychosocial Research Project; and Glenna Michaels, director of the New York City AIDS Task Force. Jane Hughes, formerly of the Fund for the City of New York and currently at the Rockefeller Foundation, also commented on portions of the manuscript and was a tireless advocate for the importance of education on the Commission's agenda. The reviewers' comments and suggestions were consistently helpful, but the Commission alone is responsible for the final version of this report.

Karyn Feiden skillfully edited the report.

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Resource Guides

The following guidebooks contain information about educational programs and resources in the New York City-New Jersey region.

American Foundation for AIDS Research, *Learning AIDS: An Information Resource Directory,* 1989. Available from R. R. Bowker, P.O. Box 766, 245 West 17th Street, New York, NY 10011. $24.95 plus tax, shipping, and handling.

Gay Men's Health Crisis, *Living with AIDS: A Guide to Resources in New York City,* 1989. Available from Gay Men's Health Crisis, 129 West 20th Street, New York, NY 10011-0022. $15.00.

New Jersey Department of Health, *New Jersey AIDS Resource Guide 1989*, 1989. Developed by and available free from the Personal Liberty Fund, P.O. Box 1431, New Brunswick, NJ 08903.

New York City Department of Health, *AIDS: A Resource Guide for New York City,* 1989 edition. Available free from New York City Department of Health, 125 Worth Street, New York, NY 10013; (212) 566-8170.

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James Lee, Administrative Assistant

Lauri Posner, Research Assistant

Foundations Supporting the Citizens Commission on AIDS

(as of November 1989)

Rockefeller Brothers Fund

The Robert Wood Johnson Foundation

Mrs. Abby R. Mauze Charitable Trust

United Hospital Fund

New York Community Trust

The Aaron Diamond Foundation

The Prudential Foundation

Fund for the City of New York

Josiah Macy, Jr. Foundation

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