

The Effectiveness of AIDS Prevention Efforts

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OTA BACKGROUND PAPER

**THE EFFECTIVENESS OF
AIDS PREVENTION EFFORTS**

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CONTENTS

Key Findings 1

Background 3

Trends in Numbers of AIDS Cases 5

- Gay and Bisexual Men 6
- Injecting Drug Users 8
- Ethnic and Racial Minorities 8
- Women 9
- Youth and Children 9

Approaches to AIDS Prevention--Changing Behavior 10

- Judging Effectiveness 12

General and Targeted Efforts 13

- Defining Groups 14

Counseling and Testing 14

- Evaluation of Counseling and Testing 16

Efforts Designed For the American People as a Whole 16

- Mass Communication Campaigns 17
- AIDS Prevention by Physicians 18

Preventing AIDS Among Injecting Drug Users 20

- Sexual Partners of Injecting Drug Users 22

Preventing AIDS in Racial and Ethnic Minority Populations 23

Preventing Heterosexual HIV Transmission to Women 24

Preventing AIDS Among School-Aged Youth 24

Preventing AIDS Among Children 25

Social Marketing 26

Economic Evaluation 28

- Findings From Economic Evaluations 28
- Potential For Greater Use of Economic Evaluation 29

REFERENCES 31

THE EFFECTIVENESS OF AIDS PREVENTION EFFORTS

OTA first addressed the question, *How Effective Is AIDS Education? (91)* in 1988. At that time, we concluded that “knowledge about the effectiveness of particular programs and of specific elements of programs has been slow to accumulate.” The Sub-committee on Health and the Environment of the House of Representatives Committee on Commerce asked OTA to take a fresh look at the question, and this background paper is the result. In 1995, there still is a need for additional research and for development and use of more carefully-refined research methods, but we know now that certain interventions can successfully reduce the risk behaviors¹ associated with Human Immunodeficiency Virus (HIV) transmission in certain groups at high risk of AIDS. The details of what is known and still unknown are reviewed in this background paper.

Most of the information comes from a series of commissioned papers written by experts on the following topics:

¹“Risk” and “risk behavior” are used in this paper to mean behavior that may lead to the transmission of HIV.

- ◆ *HIV/AIDS Prevention for Injecting Drug Users*
- ◆ *Does HIV Prevention Work for Men Who Have Sex with Men?*
- ◆ *AIDS Prevention Among African-Americans and Latinos in the United States*
- ◆ *A Review of Educational Programs Designed To Reduce Risk-Taking Behaviors Among School-Aged Youth in the United States*
- ◆ *A Review of HIV Interventions for At-Risk Women*
- ◆ *Applications of Social Marketing Principles to AIDS Education*
- ◆ *Economic Evaluation of HIV/AIDS Education and Primary Prevention*
- ◆ *HIV / AIDS Education: National Surveys, Counseling and Testing Programs and the Role of Physicians*

KEY FINDINGS

- ◆ Much has been learned since 1988 about which interventions are effective in changing risk behaviors related to HIV infection and AIDS among certain key subpopulations. Adult gay and bisexual men who do not belong to ethnic minority groups

2 The Effectiveness of AIDS Prevention Efforts

have been the most intense focus of AIDS prevention, and most is known about which interventions work in this population.

- ◆ There still are major gaps in what is known about interventions for certain high-risk populations. African Americans and Latinos account for a disproportionately large share of people with AIDS, yet relatively little research has been directed toward prevention in these population groups.
- ◆ Younger gay and bisexual men of all ethnic groups still need to be reached, and continued efforts are required for the entire population of gay and bisexual men, to make sure that those who have changed their behavior do not lapse back into early, risky behaviors. Intravenous drug use is also a very important risk factor for HIV transmission among gay and bisexual men.
- ◆ Interventions developed through in-depth preliminary work with the target population, that consist of small-group programs that are interactive and include skills development, have been among the most successful at reducing risky sexual and drug-related behaviors.
- ◆ The availability of sterile needles does not increase the incidence of illicit drug use and they can play an important role in reducing the transmission of HIV among injection drug users. Other approaches--including the increased availability of drug treatment and changes in methadone prescribing policies--while not the focus of much research, also are potential tools for reducing HIV transmission in this population.
- ◆ Sex education and AIDS education directed at school-aged youth do not increase sexual activity. Some specific sex and AIDS education programs have been shown to reduce unprotected sexual activity, either by delaying the onset of intercourse, reducing the number of sexual partners, or increasing the use of condoms.
- ◆ Voluntary HIV “testing and counseling”--the combination of HIV blood tests and the information provided before and after testing--are of variable impact, possibly because they are done differently in different places, in some cases more effectively than others. Done correctly, they have an important role in serving as a bridge to appropriate AIDS preventive, medical, and social referrals, and in some cases, altering behavior.
- ◆ Mandatory testing of certain low-prevalence populations (e.g., marriage license applicants) is an expensive way of detecting HIV positive individuals, and there is no evidence that interventions to change behavior would be effective with mandatory testing.
- ◆ Maintaining safe sex and needle use behavior over the long term once a change is made--perhaps over the course of one’s lifetime--is likely to be important for individuals at risk of

HIV, but little is known about the interventions needed to maintain these changes.

- ◆ The value of the research on AIDS prevention that has been conducted has been diminished by poor study design. Flaws include poor basic design, small study groups, short evaluation periods, and lack of control or comparison groups. (These same flaws are common to a surprisingly high percentage of research in all areas of medicine, and are not necessarily more problematic in the AIDS area than in others.)
- ◆ There is a gap between what is known about effective interventions and what is actually delivered as prevention. Community-based organizations, which deliver a significant amount of prevention, often are not able to or simply do not take advantage of current knowledge about program effectiveness.
- ◆ “Social marketing” --the application of commercial marketing strategies to societal issues--offers a possible method of inducing behavior change and maintaining non-risk behavior. Although social marketing has not been widely applied to AIDS prevention in the United States, it has demonstrated impact on other health problems in this country and on HIV transmission in some other countries. Although potentially very effective, social marketing programs can also be very expensive.
- ◆ Programs of voluntary, testing, counseling, referral, and partner

notification, as exemplified by sites funded by CDC, appear to be cost-saving in the long run, i.e., the costs of the programs are exceeded by the long-term savings (discounted) in AIDS treatment costs averted. This is true if only about 7 percent of infected people notified change their behavior to avoid further HIV transmission. Needle exchange and bleach distribution programs for injecting drug users also appear to be cost-saving.

- ◆ AIDS prevention resources could be used much more effectively, even with current technology. In some instances, social and cultural influences have impeded their use. Specifically, there has been reluctance to encourage condom use, and there are societal and legal barriers to making sterile needles available to injection drug users.

BACKGROUND

HIV disease and AIDS are progressive conditions. They begin with infection with HIV and conversion from HIV seronegative to HIV seropositive. HIV may remain in the body for up to ten years or more without causing any apparent symptoms, and an individual may be HIV seropositive for many years without being diagnosed as having HIV disease or AIDS. During this period they are infectious. A person who has not been tested for the presence of HIV antibodies or antigens is unlikely to be aware of the infection. All the while though, HIV attacks certain cells of the immune system and causes the system to

4 The Effectiveness of AIDS Prevention Efforts

erode. Eventually, the body falls prey to “opportunistic” infections (e.g., bacterial and viral infections of the respiratory and digestive tract) that are able to take hold due to the body’s weakened immune defenses. A formal diagnosis of AIDS is not made until at least one of a certain group of infections occurs or until the immune system reaches a certain, critical level of deterioration. In most cases these infections--not HIV directly--incapacitate patients and cause illness and death.

HIV is transmitted in relatively clearly defined and understood ways, all of which involve the transfer of blood, semen or certain other body fluids from one individual to another (including transmission from infected woman to fetus). Transmission occurs in the course of certain behaviors, generally sexual or those associated with injecting drug use. HIV also may be transmitted from a seropositive pregnant women to her fetus during pregnancy or birth and, in rare cases, to health care workers through needlesticks and other injuries.²

Rapid progress was made in identifying HIV as the causative agent of AIDS, in developing a test for antibodies to it, and in finding prophylaxis and treatment regimens for some of the opportunistic diseases associated with AIDS, but there is no short-term prospect for a preventive vaccine or any kind of cure. Currently available antiviral treatments are of temporary value at best. Consequently, the only

viable method for stopping the spread of AIDS is prevention, which depends almost entirely on individual behavior change (95).

Like other areas of medicine and health, public and private funding for HIV/AIDS has supported biomedical research and development more heavily than behavioral and social science research. It is noteworthy that the first preventive intervention shown through rigorous evaluation to be efficacious was a device-based technology: the HIV-antibody test for blood. Moreover, development of the blood test responded to a pervasive fear that people receiving blood products could become infected independently of their behavior. Developers of the antibody test could thus count on a large, secure market among mainstream health organizations, such as hospitals and blood banks.

By contrast, behavioral and social science research has received less emphasis and less funding, even though behavior change could prevent almost all further HIV transmission. This situation at least partly reflects the conflicting views within funding organizations and society about the behaviors associated with HIV transmission, namely sex, reproduction, and drug abuse. It has also characterized work on other sexually-transmitted diseases and drug abuse generally. Only in recent years has more rigorous research using experimental designs become common in behavioral and social science research, a development notable from the 1988 OTA report to the current background papers. Many of the

²Through the end of 1994, there were 42 documented cases of occupational transmission of HIV to health care workers and 91 possible cases (104).

economic evaluations of the early 1990s in fact grew out of such research funded by the Centers for Disease Control and Prevention (45,51,52).

The Federal Government has appropriated funds primarily through the Centers for Disease Control and Prevention (CDC) for AIDS prevention and education. Beginning in 1985, the Federal Government appropriated \$33 million for AIDS prevention and education. The appropriated funds have grown to \$589 million, the estimated expenditure for Fiscal Year 1995.

Even where AIDS prevention programs have been developed and tried, judging how effective they are remains a difficult task. It is challenging--particularly so when interventions are multifaceted and community-wide--to design studies that allow cause-and-effect to be inferred. Debate is ongoing about what types of studies and other types of evidence are sufficiently rigorous that they can be relied on to provide evidence of effectiveness, and some progress has been made in developing methods to evaluate the effectiveness and cost-effectiveness of particular interventions.

Interventions have been studied more in some communities and populations than in others, and not necessarily in relation to their importance to the current spread of HIV. Much more is known, for example, about how to prevent HIV transmission among white, gay and bisexual men over 30 than among sexually active young people or heterosexual African American or Hispanic men or women. And among injecting drug users, efforts have been directed mainly at changing their drug-taking

behavior, but not their sexual behavior, through which they can infect others. Because this paper is largely a review of literature, it reflects the balance of what has been done, which is not always the right balance for new efforts. It is particularly important to recognize that women and people of color are glaringly absent from much of the work on interventions. It is these groups among whom transmission is increasing the fastest, and they deserve higher priority in research and intervention programs than they have had up to now.

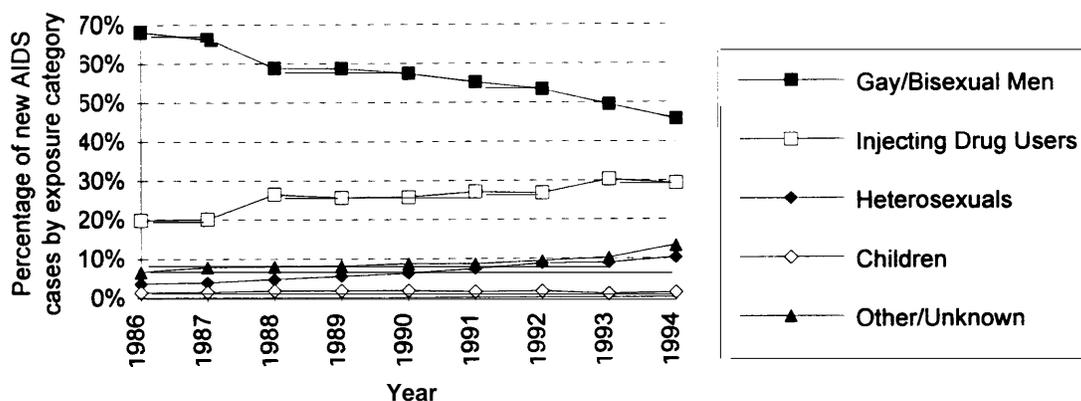
TRENDS IN NUMBERS OF AIDS CASES

The first cases of AIDS in the United States were reported in 1981. By the end of 1994, 442,000 Americans had been diagnosed with AIDS and 271,000 had died from symptoms related to the disease. The number of AIDS cases in the United States increased by about 3 percent from 1992 to 1993 and another 3 percent from 1993 to 1994.³ Women, African Americans, Hispanics, and people in the South and Northeast accounted for higher proportions of cases in 1994 than in 1993. The largest decline in the proportion of reported cases was among gay and bisexual men (figure 1).⁴

³ Because the AIDS surveillance case definition was expanded in 1993, AIDS incidence trends from 1993 to 1994 are evaluated using the estimated incidence of AIDS-defining opportunistic illnesses (103) in order to make accurate comparisons over time.

⁴ The term "gay and bisexual men" is used here to refer to all men who have sexual relationships with other men regardless of their identification or sexual orientation.

Figure 1: Trends in New AIDS Cases by Category



SOURCE: OTA, 1995.

AIDS strikes the relatively young. In 1993, it became the largest killer of Americans aged 25-44. This group accounts for about three-quarters of the cases. It also is the leading cause of death in that age group in 79 out of the 169 American cities with populations larger than 100,000 (1). In 1992, AIDS was responsible for the fourth greatest number of years of potential life lost for people under 65 years of age.⁵ AIDS was the only major cause of years of potential life lost to show a significant increase--11 percent--from the previous year (102). An estimated one million Americans are infected with the human immune-deficiency virus (HIV), the virus that causes AIDS. HIV is one of the most virulent human viruses known, with death rates exceeding 75 percent of those infected, and the ability to infect large numbers of people.

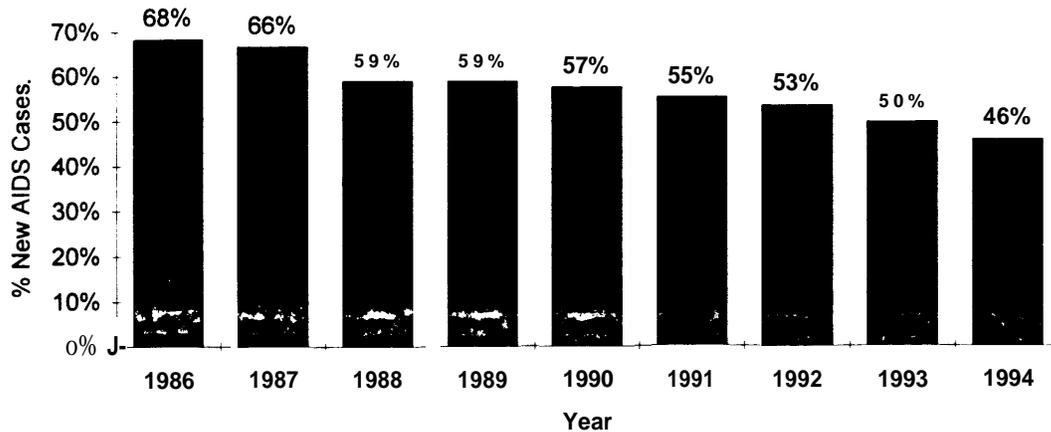
⁵ Years of potential life lost is a public health measure that reflects the impact of deaths occurring in years preceding a conventional cut-off of age, in this case 65 years old. It is a measure that takes into account number of deaths and age of decedents.

Gay and Bisexual Men

At the end of 1994, AIDS cases among gay and bisexual men, the largest group of people with AIDS, constituted 228,954 or 53 percent of the cumulative case load (figure 2). An additional 28,521, or 7 percent, of the cases are in gay and bisexual men who also inject illicit drugs (104). Gay and bisexual men represent a decreasing percentage of newly-diagnosed cases of AIDS, both because their rate of increase has slowed in recent years⁶ (1989 through 1994) and because the epidemic is growing more rapidly in other segments of the population (105). Gay and bisexual men have reduced their sexual risk behavior, including reductions in multiple sexual partners and reductions in incidence of unprotected sex, since the start of the AIDS epidemic. But gay and bisexual men continue to constitute the largest

⁶ Because the AIDS surveillance case definition was expanded in 1993, AIDS incidence trends in the study being discussed are evaluated using the estimated incidence of AIDS-defining opportunistic illnesses (103) in order to make accurate comparisons over time.

Figure 2: Percentage of New AIDS Cases Represented by Gay and Bisexual Men



SOURCE: OTA, 1995.

portion of people with newly-diagnosed AIDS, so success in controlling the AIDS epidemic depends on preventing new cases among this group.

The AIDS epidemic among gay and bisexual men, like the AIDS epidemic more generally, is a composite of epidemics among different groups, with different times of onset and patterns of spread. The rate of new cases among certain subcategories of gay and bisexual men, especially white gay and bisexual men, originally hardest hit by AIDS, is slowing (table 1). However, rates of growth are increasing among other groups less affected early in the epidemic (105). Rates of AIDS among

African American gay and bisexual men were highest in 1994 and showed the greatest increase since 1989. The rates of increase among other ethnic minority (Hispanic, Asian/Pacific Islander, and American Indian/Alaskan Native) gay and bisexual men also exceeded that for whites. In New York, Los Angeles, and San Francisco, where 27 percent of the AIDS cases among gay and bisexual men have occurred, the rate for white men decreased (20 percent, 16 percent, 3 percent, respectively) and for African American men, it increased (49 percent, 48 percent, 53 percent, respectively).

AIDS continues to spread beyond major metropolitan areas. The number

Table 1. Increases in the rate of newly diagnosed cases of AIDS among gay and bisexual men from 1989 to 1994 and the rate of AIDS among gay and bisexual men per 100,000 men in mid 1994 are shown by race and ethnic group.

Race/Ethnicity	Increase from 1989-94	Rate in Mid 1994 (per 100,000)
African American	79 percent	37.3
Hispanic	61 percent	22.6
Native American/Alaskan	77 percent	6.9
Asian/Pacific Islander	55 percent	6.2
White	14 percent	12.2

8 The Effectiveness of AIDS Prevention Efforts

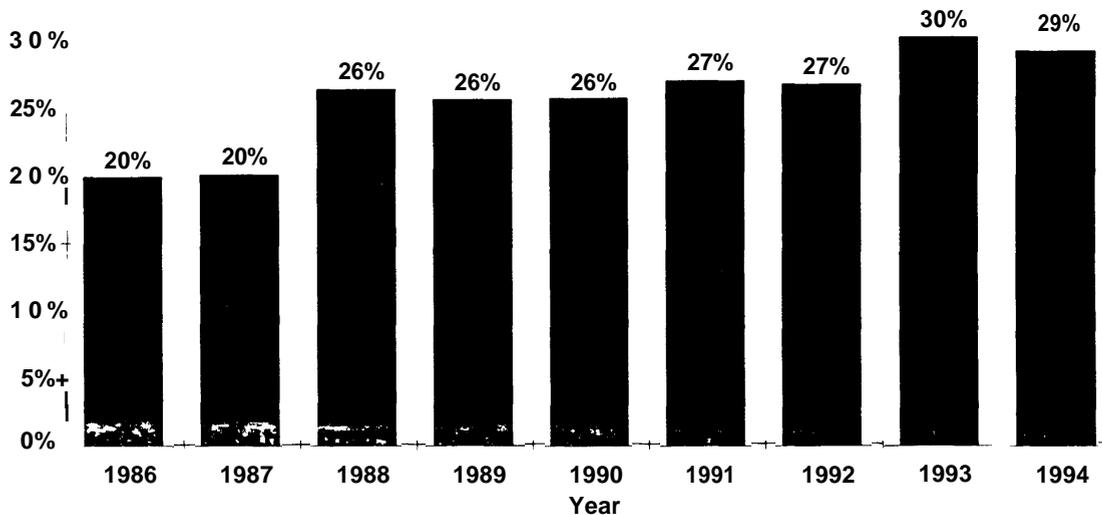
Table 2. Increases in the rate of newly diagnosed cases of AIDS among gay and bisexual men from 1989 to 1994 and the rate of AIDS among gay and bisexual men per 100,000 men in mid 1994 are shown by size of area.

Size of Area (population)	Increase from 1989-94	Rate in Mid 1994(per 100,000)
<50,000	69 percent	4.4
50,000-1 million	55 percent	10.2
>2.5 million	19 percent	24.8

of cases continues to be greatest in the West and Northeast and in urban areas, but the highest rate of growth is occurring in the South and Midwest, and in less populated areas (table 2). From 1989 to 1994, the number of AIDS cases

diagnosed among gay and bisexual men increased most in the Midwest (51 percent) and in the South (49 percent) and least in the West (21 percent) and the Northeast (13 percent) (105).

Figure 3: Percentage of New AIDS Cases Represented by Injecting Drug Users



SOURCE: OTA, 1995.

Injecting Drug Users

As many as **138,000** (32 percent) of the diagnosed AIDS cases reported through the end of 1994 **are the result of injecting drug use**⁷ (figure 3) (104). Estimates of new HIV infections in the United States suggest that injecting drug use is associated with a plurality of new

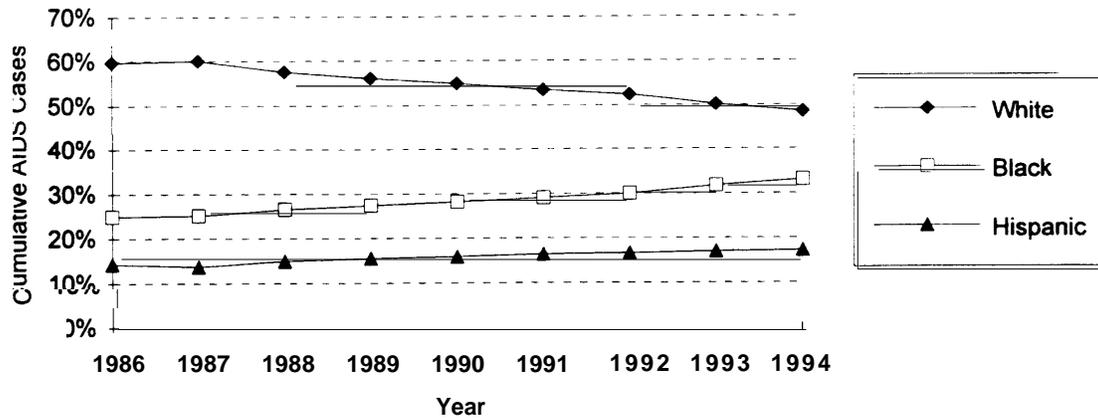
infections (43), which has implications for the future course of AIDS cases.

Ethnic and Racial Minorities

Ethnic and racial minorities represent a disproportionate and increasing share of AIDS cases in the United States (figure 4). Fifty-one percent of all cases have been among people of racial minorities, which comprise only 23 percent of the population. One-third of all cases are African Americans, 17

⁷These figures include the categories "injecting drug use" (109,393 cases) and "men who have sex with men and inject drugs" (28,521 cases), as used in the HIV/AIDS Surveillance Report.

Figure 4: Trends in Cumulative AIDS Cases by Race



SOURCE:OTA,1995.

are Latinos, 0.7 percent are Asian/Pacific Islanders, and 0.2 percent are Native Americans, compared to 11 percent, 8 percent, 3 percent, and 0.8 percent, respectively, in the population as a whole (104). Data from HIV seroprevalence studies suggest that the proportion of racial minorities diagnosed with AIDS will continue to grow in the coming years (38,75,93).

Ethnic minority groups are often viewed as homogeneous clans but, in fact, there is enormous variety in the demographic characteristics, immigration history, and cultural values of ethnic subgroups. HIV infection also is not spread evenly within these groups. For instance, there is a high concentration of HIV among Latinos in the Northeast United States, who have come mainly from Puerto Rico and the Dominican Republic. Much lower incidence and prevalence rates are reported for Latinos from the West and Southwest, who have come mainly from Mexico and Central and South America.

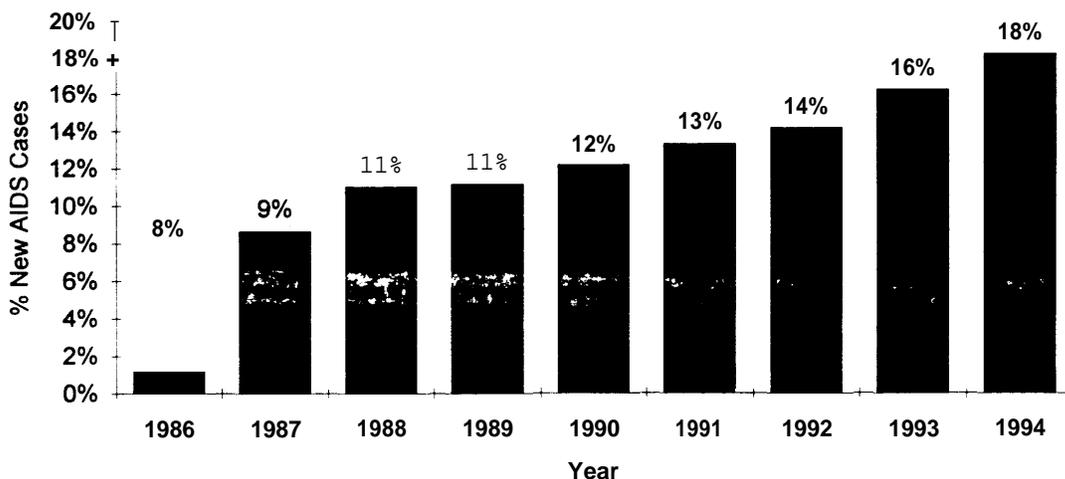
Women

The proportion of AIDS cases among women tripled from 1985 to 1994, rising to 18 percent of all new adult and adolescent cases (figure 5). Thirty-eight percent of the 14,000 cases among women diagnosed in 1994 were contracted from heterosexual sexual partners and 41 percent from injecting drugs (106). Seventy-seven percent of the 1994 cases were among African American and Hispanic women.

Youth and Children

Many young people are at risk for HIV transmission through their sexual practices. Through the end of 1994, 68,000 males and 14,000 females age 20 to 29 were diagnosed with AIDS (104). Because the period between HIV infection and onset of AIDS may be up to ten years, it is likely that many of these people, who represent almost one-fifth of AIDS cases, were infected with HIV as teenagers. Most of these cases were among gay and bisexual males,

Figure 5: Percentage of New AIDS Cases Represented by Women



SOURCE: OTA, 1995.

male and female injecting drug users, and heterosexual female sexual partners of injecting drug users.

There were 6,000 pediatric AIDS cases in the United States as of the end of 1994,⁸ representing just under 1.5 percent of the cumulative cases. The rate of pediatric AIDS cases has remained fairly constant at between 1 percent and 2 percent of the total new cases of AIDS each year.

APPROACHES TO AIDS PREVENTION--CHANGING BEHAVIOR

More than 40,000 cases of new HIV infection occur each year in the United States, despite a clear understanding of how the virus is transmitted. Although a

⁸The CDC defines pediatric AIDS as AIDS occurring in children less than 13 years old.

small number of infections arise from accidental transmission (i.e., blood transfusions, organ transplants, and needlestick injuries), nearly all infections are potentially preventable if behavior could be changed. This does not mean, however, that prevention depends entirely on persuading people to change their behaviors. It also involves access to the necessary information and technologies, and structural changes that make it easy for people to practice preventive behaviors.

With respect to Americans who are sexually active outside of a mutually monogamous relationship with an uninfected individual, behavior change means abstaining from certain sexual practices, using condoms, or both.⁹For

⁹Although refraining from intercourse with an infected individual remains the most effective way to prevent sexual transmission of HIV, the Centers for Disease Control and Prevention has found that consistent and correct use of latex

individuals who inject illicit drugs, behavior change means ceasing to inject drugs, using only sterile needles, or not sharing needles. 10

To be judged as effective, an intervention must reduce or eliminate the transmission of HIV. No prevention measure for any disease is 100 percent effective--many nowhere close to that--but they are still considered valuable. Likewise, attempts to change behavior will never stop all HIV transmission. But if an intervention even delays transmission, there is a beneficial effect both for the individual and for the course of the epidemic. An individual who avoids risk behavior even temporarily may avoid becoming infected or avoid infecting someone else. Partial success also may have benefits in diminishing the number of sexually transmitted diseases, unwanted pregnancies, and abortions.

Most premature deaths in the United States spring from "choices" people make--though not necessarily informed or "free" choices--and from social conditions that promote health or disease. These choices may be about sexual behavior, illicit drug use, smoking, drinking, diet, exercise, seat belt use, or recreation. Like these activities, HIV transmission depends on individual behavior choices. Similarly, HIV prevention is part of a spectrum of disease-fighting efforts that depend on risk avoidance, long-term behavior

condoms is highly efficacious for preventing HIV transmission (107).

¹⁰For the purposes of this paper, "needle sharing" and "needle exchange" includes sharing or exchange of syringes and other drug injection equipment.

change, and the development of policies that promote health and prevent disease. In most cases, simply telling an individual that HIV is spread through certain sexual and drug-use behaviors is not sufficient to alter that person's behavior, just as simply providing information on risk factors for heart disease or cancer is not sufficient. To be most effective, prevention strategies should provide information, motivation, skills, modification of perceived norms, and social or peer reinforcement. Just as important, long-term prevention requires long-term prevention efforts, so that positive behavior changes are sustained once they begin.

At least some attempts to change behavior to improve individual and public health historically have been beneficial, even though they have achieved only partial success. Campaigns to reduce smoking, the most important single cause of death in the United States, were initiated over three decades ago, but still about a quarter of Americans smoke. Attempts to increase exercise and improve dietary habits have found far less than full acceptance. The American Cancer Society and the National Cancer Institute recommend breast cancer screening through both mammography and clinical breast examinations for asymptomatic women aged 50 years or older. In a 1992 study, the CDC found that while 64 percent of women in the previous year had at least one of the exams, only 40 percent of women complied with the recommendation to have both (108).

Evidence shows that behavior change is difficult for most people and sustained behavior change even more so. Public

12 The Effectiveness of AIDS Prevention Efforts

health messages must compete with natural human desires, many of which are pleasurable (e.g., sexual relations) as well as with frequently appealing counter messages from entertainment media (e.g., to engage in sexual activity) or from peers (again, to engage in sexual activity or to use illicit drugs). These counter messages provide a constant challenge to AIDS prevention.

Judging Effectiveness

The biggest barrier to knowing which interventions are most effective at preventing the spread of HIV is that, considering the size of the problem and the amount of effort that has gone into solving it, too few interventions have been evaluated formally. And of those that have, many of the evaluations have not been rigorous enough to provide highly reliable information.

Some interventions have been studied in some locations and populations, but not others. More studies of gay men (mostly white) have been carried out than of any of the other important target groups, including women; younger, and non-white gay and bisexual men; adolescents and young adults generally; people with other sexually transmitted diseases; military personnel; prostitutes, and incarcerated populations. In addition, evaluation has, of necessity, focused on relatively short-term changes, in an area where the need is for changes that persist over a lifetime.

Many individuals--especially those in communities targeted for special prevention efforts--are subject to many influences on their behavior. If someone is taking part in a formal study of an

intervention's effectiveness, they will almost always be exposed to information (e.g., news reports) or events (e.g., a friend or relative sick with or dying from AIDS) external to the study. The only reliable way to determine what effects the planned intervention had, versus the effects of other influences, is to compare the behavior of people who got the intervention with that of a "control" group which, other than the study intervention, had similar inputs. The intervention and control groups should, ideally, be allocated by a method that gives an equal chance of getting into one group or the other, regardless of the individual's (or group's) characteristics, and this requires some form of randomization. The "unit of randomization" may be the individual, the community, the school, or some other unit. It is often difficult and expensive (and in some cases, not feasible) to apply randomized controlled conditions to real world intervention projects, but in fact, it is possible and the method should not be abandoned as facilely as it often is. This is not to say that other types of studies can't produce useful information, but the results of other types of studies will never be as reliable as the results of randomized studies. Even the strongly-held opinions of professionals about what does and doesn't work in AIDS prevention are not, by themselves, reliable guides for further programs.

The methodological challenges in studying and validating interventions to change behavior are even greater than for many other medical interventions (e.g., pharmaceuticals, surgical procedures). Trying to generalize the results of individual studies to the broader population is also more difficult.

Interventions to change individual behaviors can usually be considered “complex interventions,” with the following features: First, the intervention itself can be highly variable, depending on who actually conducts it. For example, the counseling portion of a testing program may vary substantially according to the style and knowledge of the provider. Much of this variability may not be easily characterized or even detected. Second, contextual factors may be important variables in the effectiveness of the intervention. For example, an educational program delivered to teenagers in a schoolroom may have a different impact than the same program offered in a community center. Third, complex interventions are characterized by a range of possible endpoints that could be used to determine effectiveness. The effects of an educational leaflet could be measured by how many are distributed, by surveys of how knowledge changes among the target population, by measuring changes in condom sales, or by tracking the prevalence of HIV.

In a practical sense, this means that an intervention found to be extremely effective in an individual study is not necessarily transferable directly to another population group or geographic area. It may be that the key factor in its success is the process by which the intervention was developed and implemented (e.g., with strong community input), rather than the actual content of the intervention. In reviewing the literature, therefore, it may not be possible to make a list of interventions that work, but it may be possible to list the characteristics of interventions and studies that have been successful.

GENERAL AND TARGETED EFFORTS

The overwhelming majority of new HIV infections continues to be concentrated in relatively few geographic areas (“communities”) and demographic groups (“populations”), though some cases occur in every community and population. Controversy has surrounded the issue of whether to target funds intensively to the communities and populations with the largest number of new HIV infections or to stress universal risk to the entire U.S. population (19,86,96). The dilemma arises for two reasons: first, concerns about stigmatizing people in targeted groups, and second, because HIV can infect anyone who engages in certain sexual or drug-related behaviors with a person who is seropositive. It has the potential to spread more widely throughout society as it has, for example, in some African countries. In the United States, however, most people with AIDS are concentrated in small segments of the population¹¹ which are largely self-contained in terms of risk behavior. If HIV were spread exclusively within clearly defined communities, it might make sense to concentrate efforts only in these communities. However, risk behavior is not completely confined in this way and individuals outside these communities may become infected.

¹¹For instance, at the end of 1994, 73.5 percent of the cumulative AIDS cases were in California, Florida, Georgia, Illinois, Maryland, New Jersey, Pennsylvania, New York, Texas and Puerto Rico. In addition, at least 88.3 percent of the adult and adolescent cases were among gay and bisexual men, injection drug users and their sexual partners.

14 The Effectiveness of AIDS Prevention Efforts

Effective AIDS prevention depends, therefore, on a combination of universal and targeted approaches. Universal education informs individuals who do not identify with a target population but may be at risk for infection. It also serves as reinforcement for targeted efforts. In order to reduce the spread of HIV, anyone, heterosexual or homosexual, who is potentially sexually active or who considers illicit drug use should understand his or her risk and how infection can be avoided. Universal AIDS prevention programs also can help reduce discrimination against people with HIV infection or AIDS. However, most new HIV infections could be prevented by intensive efforts aimed at the populations in which HIV is spreading, including gay and bisexual men, injecting drug users, and heterosexuals with high rates of sexually transmitted diseases (19). Intensive efforts in certain groups also could provide the continuing support individuals would need to maintain non-risk behavior over time.

Defining Groups

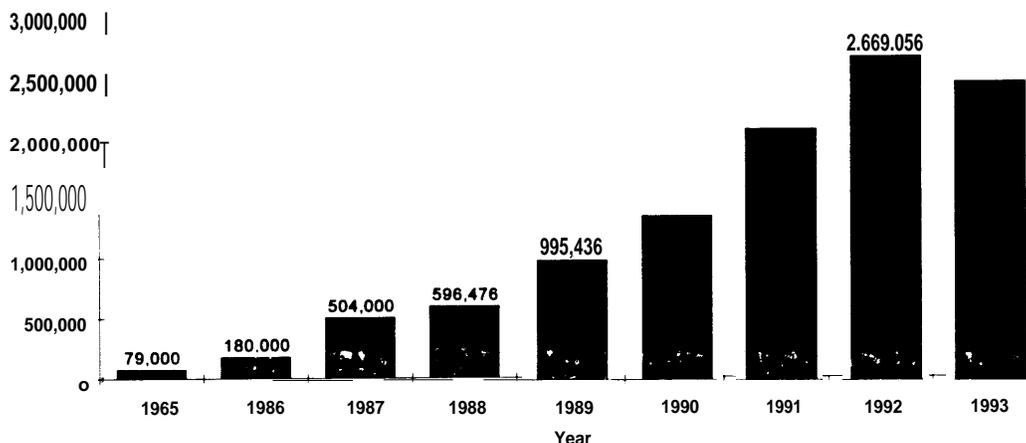
People often are defined for the purposes of AIDS education by the group or groups to which they belong--usually demographic or geographic. Many times, the groups are adopted conveniently from the epidemiological perspective, i.e., the groups for which data are reported. But in fact, the United States is a "complicated patchwork of behaviors, incomes, and ethnic backgrounds that confound simple cultural labeling" according to consumer marketers (85).

This suggests the need for a fresh look at how individuals are grouped for prevention efforts. Among African Americans, for example, there are varieties of consumption patterns and health indices depending, among other things, on location and aspects of heritage. In addition, many people fall into several groups. The commercial sector relies on statistical clusters based on geography, lifestyle, behavior, financial status, and attitudes more than on race alone. African Americans, Hispanics, Asians, and Native Americans should not automatically be lumped together as "minorities" if AIDS prevention efforts are to be most effective. Traditional consumer marketing also tends to segment the population along age lines rather than along the "risk group" lines suggested by epidemiological data. With half of the new infections occurring in individuals under 25, adolescents at risk may have more in common with each other than with individuals of similar race, ethnicity, or sexual orientation, but of different ages.

COUNSELING AND TESTING

The CDC spends substantial funds on its program of counseling, testing, referral, and partner notification (CTRPN), much of which has been mandated by Congress. The program began in 1985 with 79,000 people tested. By the end of 1993 11 million tests had been performed (figure 6). An additional 5 million tests had been performed in private physicians' offices and health maintenance organizations through 1990 (101).

Figure 6: HIV Tests in CDC Sites by Year



SOURCE: OTA, 1995.

The four main functions of counseling and testing, according to CDC are: (1) to provide a convenient opportunity for persons to learn their current HIV serostatus; (2) to help initiate behavior changes to avoid infection or, if already infected, to prevent transmission to others; (3) to refer individuals to additional medical and other services as needed; and (4) to provide prevention services and referrals to sex and needle-sharing partners of people with AIDS or HIV infection. (1 11). Counseling and testing also protect the blood supply and provide a method to notify sexual partners of seropositive individuals of potential risk (45).

In addition to the testing itself, each person is to receive counseling both at the time of providing a blood sample and upon receiving test results. The pre-test counseling is intended to assess the client's personal risk for HIV infection, discuss the elements of the test, and answer questions. The post-test counseling informs the client of his or her serostatus and discusses its

implications. If the result of the test is negative, the counselor should discuss the importance of adopting or continuing risk reduction behaviors. If a client tests positive, the counselor also provides emotional support and referrals for appropriate medical and other services. Many programs include a mechanism for notifying partners of infected individuals (36). Unfortunately, pre- and post-test counseling, as conducted currently, often are inadequate to assess the potential for risky behavior, and in many places, there are too few medical and prevention services available for referral.

Except for uniformed military personnel, Jobs Corps applicants, foreigners who attempt to immigrate to the United States, and some other selected groups (e.g., State Department employees, sex offenders, prostitutes, prisoners, blood donors), most HIV testing has been voluntary. One exception was an Illinois law requiring that couples be tested for HIV and receive their results before they could get a marriage license. In the six months

after the law took effect, only eight out of the 70,846 applicants tested seropositive. During the same time, applications for marriage licenses decreased by 22.5 percent, and licenses issued to Illinois residents in surrounding states increased. Research suggests the possibility that residents most likely to test seropositive were most likely to seek out-of-state licenses. Testing costs were paid by the applicants, not by the state, but the cost per case of HIV identified was estimated to be \$312,000, compared with \$2,000 per case identified through the state's voluntary counseling and testing program. The law was repealed and the Director of the Illinois Department of Public Health concluded that the experience "provides a strong argument against widespread mandatory or publicly supported HIV antibody testing of low-prevalence populations" (100).

There also is evidence that individuals, especially high-risk individuals, are more likely to come forward if they have the option of anonymous testing. In an Oregon study, anonymous HIV testing, as opposed to confidential testing, increased the number of people who came in to be tested and increased the proportion found to be seropositive (28).

Evaluation of Counseling and Testing

Counseling and testing programs have been difficult to evaluate because of the variety of study populations, research designs, methodologies, analyses, and results (42). In addition, testing is often performed without counseling (though CDC's guidelines require counseling with testing) (41). There is evidence that

counseling and testing can lead to reduced sexual and drug risk behavior associated with viral transmission (42,45). The effects vary, however, by serostatus, population, and the quality of the counseling and testing service.

The single area with clear data for behavior changes associated with reduced risk of HIV transmission following counseling and testing concerns both gay and heterosexual discordant couples (one partner infected with HIV and the other not). It is important to note, however, that this finding comes from programs in which the counseling extended beyond that typically received by most people who are tested. In several studies of discordant couples, there was a substantial increase in condom use over time. These results suggest that intensive counseling over a sustained period may be effective in reducing risk behavior for individuals at high risk for HIV infection (21,53,81,98,114). They may point to ways to improve counseling for other groups.

EFFORTS DESIGNED FOR THE AMERICAN PEOPLE AS A WHOLE¹²

Education and prevention efforts aimed at the American people as a whole have several aims. In addition to the obvious aim of promoting safe practices, others are to reduce discrimination against infected people and to reduce anxiety among low-risk people by giving

¹²This section is based largely on a paper prepared under contract to OTA by Zimmerman, Pham, and Steinman (120).

them good information about how HIV is and is not transmitted. To a large extent these efforts are intended to reach sexually active heterosexual youth and adults for whom there are few targeted community-based programs. This group accounts for relatively few AIDS cases, but the percentage of heterosexual adolescents and adults among AIDS cases who do not belong to a defined high-risk category is growing. From 1988 to 1994, the percentage of newly-diagnosed AIDS cases in this group increased from 5 percent to 10 percent. AIDS is becoming a particular problem in some heterosexual subpopulations, particularly African-Americans and Hispanic-Americans (7,74).

Knowledge about HIV transmission has increased from 1987 to 1992, though there continue to be significant gaps (88). This increased knowledge may be explained by a combination of several influences, including media attention, high profile cases such as Magic Johnson and Ryan White, and school-based AIDS education. Americans are more likely to understand how AIDS can and cannot be transmitted. However, in 1992, 55 percent did not know whether latex condoms and natural-membrane condoms conferred the same protection against HIV/AIDS, and 60 percent did not know whether oil-based lubricants can cause latex condoms to break, two important factors in condom effectiveness.

Knowledge usually is necessary for behavior change, but there is no clear and consistent evidence that accurate AIDS knowledge alone necessarily changes behavior (4). Many sexually active heterosexual Americans may be at

modest risk for HIV transmission because they engage in sexual activity with more than one sexual partner, often without a condom (2,7,8,23).¹³ Despite the risk for transmitting HIV through heterosexual activity, few interventions have been evaluated to determine their impact on this behavior.

Mass Communication Campaigns

National surveys indicate that television is the most frequently cited source of information about AIDS. Thus, the mass media are well-positioned to play the dual role of influencing people who are not reached by other interventions and serving to reinforce non-risk behavior for those who are. The CDC developed America Responds to AIDS (ARTA), a national public service advertisement and public relations campaign designed to reach as many Americans as possible with information about HIV and how to prevent its spread. The campaign ran from 1987 to 1991, using electronic and print media, as well as public events. ARTA focused on providing information about AIDS rather than urging behavior change. It shied away from strong prevention messages, because the behavior changes needed to reduce the spread of HIV involve controversial topics such as sexual behavior and drug use. For instance, the public service announcements usually failed directly to address risk-reduction behaviors such as the use of condoms. In addition, there

*³ Most Americans who engage exclusively in heterosexual sexual activity are at less risk for infection than most gay and bisexual men simply because the incidence of HIV is lower among heterosexuals than among gay and bisexual men.

are inherent limitations to public service announcements as opposed to paid commercials because television and radio station personnel determine if and when the commercials run. They are motivated primarily by the needs of the station, not by public health considerations. Further, to be most effective, mass media campaigns must be implemented for a sustained period of time and heard repeatedly, which is not likely with public service announcement campaigns. The media potentially offers an important source of AIDS prevention because of its reach, but the opportunity has not yet been used effectively.

AIDS Prevention by Physicians

Physicians are seen by the public as sources of reliable health care and prevention information (14,17) and physician counseling can lead to healthier behaviors (65). As yet, however, physicians have not played a major role in informing people about their risk of infection with HIV, or counseling them about how to avoid it. They represent a potential source of influence for the 60 percent of Americans who see a physician each year--though many of the people at highest risk may not see a physician.

The U.S. Surgeon General, the CDC, the Agency for Health Care Policy and Research, and many professional medical associations have encouraged physicians to assess their patients' risk behaviors and counsel them to prevent HIV transmission, but no clear guidelines about what steps to take with patients have been put forth. It appears that most physicians do not counsel about HIV or AIDS (6,35,110).

(Physicians often do a poor job with other prevention opportunities as well, e.g., influenza vaccines for older people, rubella screening for potentially pregnant women.)

Lack of information about and training in AIDS, discomfort in addressing sexual conduct, and incorrect assumptions about high risk behaviors may be holding back some physicians from counseling. Some research has shown that physicians are uncomfortable with AIDS, at least partially because most people with AIDS are gay or are members of other stigmatized groups (19). Other barriers to effective physician prevention efforts include rushed visits and limited or nonexistent reimbursement for counseling and testing. Finally some people cannot afford to visit doctors, choose not to see them regularly, or see them in settings not conducive to prevention counseling (69).

A nationwide program of AIDS Education and Training Centers (AETCs), set up through the Health Resources and Services Administration of the Public Health Service, began in 1987 to train physicians, nurses, and dentists. Most AETC activities are for training health care personnel to care for people with AIDS, but about 25 percent of the training activities are directed towards prevention (13), and there also are private sector continuing medical education programs on the topic. Few studies have evaluated the effects of training physicians or other health care workers, but some evidence suggests that training may improve risk assessment and prevention counseling for HIV (29,44). Any future efforts

should be subjected to rigorous evaluation.

PREVENTING AIDS AMONG GAY AND BISEXUAL MEN¹⁴

Carefully designed studies have demonstrated that interventions can be effective in lessening risk behavior among gay and bisexual men. The interventions studied included individual or small-group counseling, HIV counseling and associated testing, and community approaches. In these studies, reduction in risk behavior was defined as statistically significant increases in condom use or reductions in anal intercourse without a condom. The studies showed that positive behavior changes can be both short-term and relatively long-term (greater than one year). Evidence suggests that interventions can be effective with gay and bisexual men generally, including African Americans and adolescents. No studies of Latinos have been published, however.

Multiple session, small group counseling can result in both short-term and long-term increase in condom usage and less unprotected sexual activity (57,112), including with African American gay and bisexual men (83). No controlled studies have been conducted considering the effects of counseling on gay and bisexual adolescents, but in two uncontrolled studies, reductions in risk behavior were associated with counseling interventions.

Data suggest that HIV counseling and testing may play a role in HIV risk reduction for gay and bisexual men (42). Gay and bisexual men who have been tested tend to engage less often in sexual risk behavior. However, it is difficult to isolate the effects of HIV counseling and associated testing from other factors that may affect risk behavior, including the same personal factors that cause some people to be tested and others not to be.

Community-level interventions seek to modify the norms of entire groups of people in which there is a high level of HIV infection, so that there can be social and peer reinforcement for non-risk behavior. Several projects included pre- and post-intervention evaluations that suggest that community interventions may have an effect on reducing risk behavior (11,54,55). For example, the STOP AIDS Project in San Francisco conducts outreach and workshops for gay and bisexual men. An evaluation, conducted with the Center for AIDS Prevention Studies, revealed that of the last 505 pre- and post-test evaluations, 25.1 percent of the men reported unprotected intercourse prior to the workshop and 19.4 percent after, with greater differences observed for seropositive individuals (9). (None of these studies have randomized communities to have the intervention or not, or have had control communities, so it is not clear how much of the change can be attributed to the intervention.) In a study of small-town gay men who go to bars, training a small group of "trendsetters" in non-risk sexual behavior altered the norms of the group. "If risk reduction is an expected and accepted norm within one's peer and social network, individuals will be

¹⁴This section is based largely on a paper prepared under contract to OTA by Coates et al. (10).

encouraged to adopt precautionary patterns (58).”

Determining whether HIV infection prevention is working “on the ground” is difficult because of the small number of controlled studies and the lack of consistent, established surveillance systems to provide regular and reliable information about HIV transmission rates. Studies have found sharp declines in risk behavior among gay and bisexual men in San Francisco, New York, and other cities during the 1980s. Reported behavior changes early in the AIDS epidemic among gay and bisexual men were among the most profound in public health (11,27,71,72,73). There have been declines in seroconversion from HIV negative to positive (50), declines in potentially unsafe sexual relations (20,24), declines in other sexually transmitted diseases, and declines in the rate of new AIDS cases. For example, the San Francisco Department of Health projects the number of people in that city who will become infected with HIV between 1994 and 1997 at 1,000 per year (an estimated 650 among gay men), down from 8,000 in 1982. These changes appear to have continued into the 1990s (89) and cannot be explained simply by saturation of high-activity core groups (50). They almost certainly represent benefits gained through behavior change (but not necessarily from particular programs).

It must be underscored that while there is evidence of improvement for gay and bisexual men as a group, there continues to be high rates of new infections among some racial and ethnic groups and among younger gay and bisexual men. Young gay and bisexual

men are forging another wave of HIV infections. Existing intervention strategies do not appear to be successful in reaching these populations. In addition, there is some indication that gay and bisexual men who initially adopted low-risk behaviors may have failed to maintain these behaviors (11,27,56,94). These data collectively demonstrate a need to focus on and find more effective interventions for younger and non-white gay and bisexual men, while continuing to pursue prevention and maintenance strategies for all gay and bisexual men.

PREVENTING AIDS AMONG INJECTING DRUG USERS¹⁵

The exchange of blood through sharing of injecting drug equipment by two or more people is the second most common cause of HIV transmission after unprotected sexual intercourse between men. The major mechanism for the spread of HIV infection among injecting drug users is injection with traces of blood from contaminated needles or other paraphernalia previously used by an HIV infected individual. Providing previously used equipment to another injection drug user is often seen as an act of solidarity or as a service for which one may legitimately charge a small fee.

Transmission of HIV within the population of injecting drug users may be lessened by eliminating or reducing illicit drug injection, reducing needle sharing, or using sterile injection equipment. Without intervention, HIV

¹⁵This section is based largely on a paper prepared under contract to OTA by Des Jarlais (16).

can spread rapidly among injecting drug users. In certain areas, the rate of infection has increased from 10 percent to 40 percent or more within just one or two years (17). In turn, HIV is often spread from infected injecting drug users to their sexual partners.

Successful drug detoxification and treatment are the best methods of AIDS prevention among injecting drug users but are not a completely satisfactory solution. Only 15 percent of active drug users are in treatment on any given day, and there are not enough treatment slots to meet the demand from drug users. In addition, many drug users do not want to enter treatment. Treatment programs can lead to substantial reductions in illicit drug use (47), but treatment does not guarantee ending risk behavior or preventing a return to drug use. Education at drug rehabilitation sites and “street outreach” to active drug users, including education, needle exchange, and instruction on needle sterilization were attempted in some places.

The National Institute of Drug Abuse (National AIDS Demonstration Research /AIDS Targeted Outreach Model) funded street outreach prevention efforts in 41 projects in 50 cities. These programs offered participants information about HIV and AIDS, personal risk assessment, and HIV counseling and testing. Results were somewhat mixed, but the interventions were followed by a decline in needle sharing and an increase in sterile needle use.

Needle Exchange

Needle exchange and bleach disinfectant efforts have proven

controversial, with some critics asserting they encourage illicit drug use or that they implicitly endorse the use of illicit drugs. In the United States, unlike in several European countries, no Federal funds may be used to support exchanges of needles or any distribution of sterile injection equipment to illicit drug users. In addition, many states prohibit the sale of such equipment without a prescription. By contrast, providing legal access to sterile injection equipment, either through expanded pharmacy sales, needle exchange or both is now a standard part of HIV prevention in many other industrialized countries.

Local needle exchange programs have been established in at least 102 U.S. sites through at least 37 programs. Programs provide a sterile needle in exchange for a used one. In addition, many of the programs make referrals to drug detoxification and treatment programs and distribute condoms, bleach, health pamphlets, and other AIDS prevention information. About half of the needle exchange programs are legal under the law of the state in which they operate. About one-quarter are not legal but receive support from a local elected body. The remainder operate outside of the law and without such support (52).

Several U.S. needle exchange programs have been evaluated. In every published study, including one conducted by the General Accounting Office (GAO) in 1993, no evidence was found that the programs result in any increase in illicit drug use. In fact, one program studied by GAO found a decrease in drug use in association with the implementation of a local effort (52). In addition, there is evidence that

outreach programs and needle exchange programs uncovered demand for drug detoxification and treatment and were a significant source of referrals to such treatment (3,49,79).

The National AIDS Demonstration Research/AIDS Targeted Outreach Model and other studies (18) have found that HIV infection rates are much lower in areas that permit over-the-counter sales of sterile injection equipment as opposed to areas that restrict them by requiring prescriptions for their purchase. In one study, incidence of HIV infection was lower by half in areas with legal over-the-counter sales of needles (30). Studies of injecting drug users participating in needle exchange programs in several U.S. cities also have found a low rate of HIV transmission among participants (39,78,80,82).

A study of hepatitis B and hepatitis C infection in Tacoma, WA provides good evidence for the effectiveness of needle exchange programs on reducing transmission of blood-borne viruses, particularly because the study used biological outcomes and a controlled experimental design. Failure to use the local needle exchange program was strongly associated with both hepatitis B and hepatitis C infection. Injecting drug users who did not use needle exchange were five times as likely to become infected with hepatitis B and seven times as likely to become infected with hepatitis C (18,40).

Taken together, these data and others provide evidence that access to sterile

injection needles has a beneficial effect on the drug-related behavior that puts individuals at risk for contracting HIV.

In addition to attempts to prevent the sharing and reuse of needles, there are interventions which involve teaching illicit drug users to clean their equipment with bleach which kills HIV. However, studies have raised questions about the effectiveness of this type of intervention, and it is not clear there is a relationship between self-reported use of bleach disinfectant "in the field" and protection from HIV infection.

Sexual Partners of Injecting Drug Users

HIV also is transmitted from infected injecting drug users to their sexual partners. By the end of 1994, heterosexual sexual activity between injecting drug users and individuals who do not inject drugs accounted for about 16,000 cases of AIDS (104). Injecting drug users have changed their sexual risk behavior more than heterosexuals in the United States generally (62), but studies have shown less success in persuading them to change their sexual risk behavior than their needle-sharing behavior (31). Thus, sexual relationships between injecting drug users and their partners continue to provide a route of HIV transmission into larger populations. Finding effective ways to persuade injecting drug users to avoid risk behavior during sexual activity is a critical challenge in slowing the spread of AIDS.

PREVENTING AIDS IN RACIAL AND ETHNIC MINORITY POPULATIONS¹⁶

Research focusing on AIDS prevention among minority populations has lagged behind research on other groups, despite the disproportionately high (and worsening) rate of HIV infection among African Americans and Latinos. Before 1988, only one research report focusing on a minority population had been published. In 1995, 41 reports, published (or accepted for publication) in peer reviewed journals, focused entirely or mainly on African Americans, Latinos, or both. (There still have been no studies published on Native Americans or Asian/Pacific Islanders.) Of these studies, 13 were randomized trials. In four of those, the interventions were very effective, and in five others, of moderate or mixed effectiveness. Even from this small literature, however, some general findings emerge, and they are consistent with interventions in other populations.

The most successful interventions were developed through extensive preliminary work with the target population, and used formal behavior change theory in their development. The preliminary work consisted mainly of focus groups and individual interviews. These exchanges provided information, for instance, about the barriers to safer behavior and about the level of skills that people had to deal with difficult situations. They also served to help develop and test the research

questionnaires and role playing materials before formal data collection began.

The four most effective interventions emphasized behavioral skills and practice (e.g., practice for teenagers in refusing to engage in unsafe behavior, negotiating about condom use, and putting on condoms), and were generally more interactive and less didactic than the less effective interventions. African American adolescents were the target of two of the particular programs that were most successful, and the interventions were, in one case, eight weekly group meetings of 90 minutes to two hours each, focusing on behavioral skills, condom use skills, and refusal skills; and in the second case, a five-hour program of information, videos, games, exercises, and skills practice. A third successful program, this one for high-risk mostly African American women, consisted of a series of group sessions with a variety of information, role playing, and other activities. The fourth program was for African American and Latino sexually-transmitted-disease patients, and consisted of culturally appropriate videos, 20-minute group sessions, skills building, role playing, and discussions.

There are large gaps in the AIDS prevention research for minority populations. Most strikingly, almost no work has been done with African American and Latino drug users or gay men, two groups affected heavily by the AIDS epidemic. Interventions targeting adult men who are not injection drug users have been rare, except for studies of STD patients. Adolescents have been studied to some extent in schools, but not in neighborhoods or juvenile

¹⁶This section is based largely on a paper prepared under contract to OTA by Marin (70).

detention settings, where many of these youth are more likely to be.

Research has gone slowly with African Americans and Latinos for several reasons. Funding agencies have not specially targeted these groups, and researchers may have shied away from taking on studies of high-risk, hard-to-reach populations. Few non-minority researchers have demonstrated interest in these groups, and there are too few minority researchers in positions to undertake the needed work.

PREVENTING HETEROSEXUAL HIV TRANSMISSION TO WOMEN¹⁷

Little is known about the effectiveness of AIDS prevention activities targeted towards women. Multiple counseling and skills sessions targeted at female injecting drug users, female sexual partners of injecting drug users, and inner-city or low-income women seem to provide a benefit in terms of increased condom use (26,87). A controlled study of a program of peer outreach combined with distribution of written material containing risk-reduction strategies increased condom use among female sexual partners of injecting drug users living in public housing projects (99). A methodologically sound HIV counseling and testing study found no benefit at either two weeks or three months (48).

¹⁷This section is based largely on a paper prepared under contract to OTA by Ehrhardt, Exner, and Seal (25).

As with many other subpopulations, often studies enlisted very small samples, failed to provide enough information to be assessed, had unclear or very short follow-up periods, were not randomized, or did not use control or comparison groups. This deficiency is a serious matter given the rate of increase in AIDS cases among women. More work is needed in this area in order to develop effective prevention programs. The variety of techniques studied must be expanded, especially to include community-level interventions. Maintenance of non-risk behavior should be studied as well.

PREVENTING AIDS AMONG SCHOOL-AGED YOUTH¹⁸

There have been various studies evaluating school, community, and health clinic-based sex and AIDS education and prevention efforts targeted towards youth. The weight of the evidence indicates that sex and AIDS education programs, in general, increase the use of condoms (or other forms of contraception) by a small amount, and that more targeted programs can increase condom use by a greater amount. Still, overall, there are large gaps in knowing how to prevent HIV transmission among young people.

All 50 states either mandate or recommend AIDS education in their schools (15,34). Schools have the advantage of reaching almost every young person in society before he or she begins potentially risk-associated

¹⁸This section is based largely on a paper prepared under contract to OTA by Kirby (59).

behavior. There is widespread public support for sexuality and AIDS education in the schools (32,33,67), but there has been conflict in some communities over the content of such education. Some believe that only abstinence until marriage should be discussed, while others believe that contraception and other sexuality topics should be covered as well. Those who favor only abstinence fear that further discussion would encourage youth to engage in sexual activity that they otherwise would avoid, thereby potentially increasing HIV transmission along with other undesirable outcomes. People who favor discussion of additional topics along with abstinence are concerned that abstinence alone is not a sufficient lesson, because many teenagers still would engage in sexual activity.

Studies have found no evidence that curricula focusing only on abstinence have an impact on delaying the onset of sexual intercourse. However, limitations in the design of these studies may have obscured program impacts. On the other hand, data strongly support the conclusion that sexuality and AIDS education that include discussions of abstinence and contraception in combination with other topics such as resistance skills do not hasten the onset of sexual intercourse for students who have not already initiated such activity (46,60,76,97,116). In fact, there is evidence that these more sexual educational and AIDS prevention programs result in a lower incidence of sexual intercourse, and for individuals who do engage in sexual activity, fewer sexual partners and greater use of contraception (46,60,64,68,115). At the

same time, none of the interventions resulted in increased or decreased frequency of intercourse for individuals sexually active prior to the beginning of the study.

Some other methods also have been found to have at least marginal value in reducing HIV transmission. Multiple-session counseling (5), counseling connected to other services (118), and a wide-ranging program of community prevention activities (61,113) all have some promise, but need additional refinement and evaluation.

PREVENTING AIDS AMONG CHILDREN

HIV can be transmitted from infected mother to her fetus during pregnancy, at birth, or during breast feeding. An estimated 7,000 births occur each year to HIV-infected women in the United States. All of these children initially test seropositive because they carry certain elements of their mother's immune system, though about three-quarters of them will become seronegative and suffer no manifestations of HIV disease. In fact, about 25 percent of these children are actually infected with HIV, and virtually all of them will develop AIDS.

HIV transmission among this population may be significantly reduced if the infected mother and newborn are treated with Zidovudine (AZT). In a randomized clinical trial, only 8 percent of the children born to HIV-infected mothers were born infected if the mother took AZT during pregnancy and birth. (37). The effectiveness of this

intervention in the community depends on the mother's knowledge of her serostatus, her access to prenatal care, her confidence in her doctor, and her ability and willingness to use AZT. The effect seen in the clinical trial also might be larger than it is likely to be in the community.

Studies have shown that a program of testing only pregnant women who appear to fall into a traditional exposure category for HIV infection will fail to identify many of the women who in fact are seropositive (22,37). Consequently, a program of voluntary testing might be a better method to screen for HIV among pregnant women. Most pregnant women who may be at risk for HIV infection will agree to be tested if they are in prenatal care and the service is offered. In an eight-month pilot study done in 1989 in six Los Angeles County public clinics, 76 percent of 9,069 women accepted voluntary HIV testing. Results also suggested that when the HIV antibody test was presented as a routine rather than a special, optional test, acceptance was nearly universal (12). In 1987, routine prenatal HIV screening was offered as part of a battery of tests to 3,472 women at Grady Memorial Hospital, which serves a poor, intercity population in Atlanta. The HIV test was singled out from the others and the women received written information about the test and its implications, along with a consent form agreeing to the test. Even though at the time there was no treatment known to prevent transmission from infected mother to child, 96 percent of the women agreed to be tested (66). Testing and counseling pregnant women can be an effective part of reducing perinatal HIV transmission if

seropositive women have access to AZT and to related medical care and support services.

SOCIAL MARKETING¹⁹

People and their needs change constantly, and this includes the information and stimulation they need to practice healthy behaviors. Even proven methods may have to be tailored (e.g., through community-based planning) to be successful in different subpopulations and over time. An effective approach may be social marketing, which seeks to borrow consumer product marketing techniques from the private sector and use them for health promotion. Social marketing has been talked about but little used in AIDS prevention in the United States, though it has been used in other countries for AIDS prevention and for other health promotion campaigns. Social marketing takes the approach that prevention must be "sold" and that there may be a need to "resell" it even to the "converted" in order to maintain behavior change, just as there is with consumer products. "No one at Coca Cola would argue that selling Coke is something you accomplish once and forever, especially when everyone knows about Coke and likes it. Selling Coke is something you do every day, in ever new ways, to meet an ever changing consumer (92)."

Social marketing in an AIDS prevention context would use private-sector product marketing approaches to

¹⁹This section is based largely on a paper prepared under contract to OTA by Rabin and Porter (84).

“sell” HIV prevention to the public. It would move beyond traditional health education to provide a framework for constantly adapting prevention efforts to new audiences and audiences who are always changing. It would employ market research, segmentation, diverse marketing channels, measurable outcomes, constant evaluation for continued efficacy and program redesign where needed. It would identify and attempt to meet a consumer need with the goal of sustaining behavior change over a period of time. In exchange for alterations in behavior, social marketing would offer a desired benefit, one that is found through rigorous consumer market research. Social marketing research has shown that desired benefits often have more to do with social acceptance or status than “health.” For example, future health benefits may be insufficient to persuade teens to avoid smoking, but they may be willing to do so to escape current social stigma. With respect to AIDS, social marketing would seek to address questions such as: What is the benefit of abstinence for teenagers when sexual activity is considered a rite of passage by one’s peer group? How can condom usage be increased when condoms often are associated with gay people, a stigma for some, or a lack of trust between partners? What is the benefit of avoiding certain sexual activities versus the risk of contracting a virus that may kill you in 10 to 15 years?

Social marketing considers perceived benefit, consumer acceptance, price (including monetary value, time, and social cost), sacrifice of behavior possibly considered pleasurable and convenience of outlets. It takes as a given that effective promotion requires a

wide array of creative tactics and repetition involving professional message design. For each AIDS prevention behavior, there is competing pressure to stray from that behavior, so a single exposure to even the most effective message or adopting the “right” behavior may not be enough. Social marketing would “sell” prevention again and again to the same target audiences.

Social marketing approaches have been used in cardiovascular risk reduction, smoking cessation and population planning, as well as in U. S.-funded AIDS prevention efforts in other countries. For example, the National Cancer Institute developed the 5-A-Day campaign to increase fruit and vegetable consumption. It employed marketing segmentation to define target audiences and followed a consumer-based approach to the design of media messages. Diverse marketing channels were chosen to deliver messages to key groups. Promotional materials were placed in over 30,000 retail establishments. There were television appearances by Olympic gold medalists.

In April 1993, the CDC established the Prevention Marketing Initiative (PMI), which uses a social marketing approach. CDC has worked with community-based organizations to develop demonstration projects targeted to young people in Phoenix, AZ, Sacramento, CA, Northern Virginia, Nashville, TN, and Newark, NJ. It also has produced 12 public service announcements for radio and television with messages about abstaining from sex and using condoms. As yet, there has been no outcome evaluation of PMI. The program entails considerable

expense, and many questions remain about whether it can achieve an acceptable level of effectiveness to make it worthwhile.

ECONOMIC EVALUATION²⁰

A central question for policymakers is which strategies are most cost-effective in preventing further HIV infection? The aim would, of course, be to choose the mix of interventions that would prevent the largest number of infections with the amount of money available for AIDS prevention programs. As is the case in most areas of medicine and health, the cost-effectiveness information that one would need ideally to make “rational” choices is quite limited. Only in recent years has sufficient evidence of the efficacy and effectiveness of interventions accumulated to begin to support such analyses.

A total of 25 economic evaluations of AIDS primary prevention interventions meeting minimum methodological criteria were found in the published literature in 1995 (90). Some of these studies look at interventions that are not basically “educational,” such as screening donated blood, and screening health care workers, and are not discussed in this report. Interventions that do fall within the scope of this report and are the subjects of economic evaluations are:

- ◆ voluntary counseling and testing of injecting drug users, high- and low-

risk populations (based on a model), the general public, pregnant women, and women age 13-44;

- ◆ mandatory testing of marriage license applicants and premarital couples,
- ◆ notifying partners of infected people and injection drug users;
- ◆ bleach distribution to injection drug users;
- ◆ needle exchange for injection drug users; and
- ◆ treatment of drug dependency.

Many of the interventions--even some for which there is some evidence of efficacy and effectiveness--discussed earlier in this report have not been subject to economic analysis. This includes the important category of small group counseling (except as included in the studies of injection drug users) and virtually all the large-scale education programs aimed at the public and at various risk groups.

Findings From Economic Evaluations

The major types of economic evaluation--cost-effectiveness, cost-benefit, and cost-utility analyses--all take into account the costs and effects of interventions. In the case of AIDS prevention, as with many other preventive services, the costs of intervening occur in the present, and many, if not all, the benefits occur sometime in the future. Discounting is a technique used to allow all the costs and benefits to be expressed in current dollars, recognizing that money spent today is worth more than the same amount of money spent 10 years from now. Having everything in the same currency is necessary for making

20 This section is based largely on a paper prepared under contract to OTA by Sisk (90).

comparisons, but money spent today must materialize in a particular budget, while money counted in the future need not.

Programs of counseling, testing, referral, and partner notification, as exemplified by the CDC-funded sites, produce benefits greater than their costs. If only about 7 percent of the infected people notified subsequently changed their behaviors to avert further transmission, savings in discounted lifetime AIDS treatment costs (about \$85,000 in 1990 dollars, 6 percent discount rate) would more than compensate for program costs. If savings in future earnings are added, net benefits would exceed costs if only slightly more than 1 percent of infected people notified averted further spread of HIV.

A similar pattern emerges for several interventions targeted to injection drug users. Savings in treatment costs avoided are likely to exceed program costs for counseling and testing, partner notification, and bleach distribution. Even using conservative assumptions about injection and sexual behavior for more controversial needle exchange programs, their savings in treatment costs are likely to outweigh program costs.

The results for testing marriage license applicants were less clear, partly because there is little information about how effective this type of testing would be in changing sexual behavior. Testing women of childbearing age would produce most benefits in preventing infection among adult contacts, and less in preventing the birth of infected

newborns, so it really reflects testing part of the adult population. Screening women could potentially produce more benefits than the costs of the program if it were targeted at high-risk women and the HIV prevalence were above a certain level.

Potential for Greater Use of Economic Evaluation

The use of cost-effectiveness analysis and other forms of economic evaluation in AIDS prevention policymaking is limited by the still meager literature on the topic and by the variability in analytic methods used. This situation is changing, however, as the potential value of this type of work is appreciated and more is being undertaken by independent academics and others. In addition, CDC is encouraging the use of economic analysis by the HIV Prevention Community Planning Groups that it funds. Developments in the field of cost-effectiveness analysis itself may also help solidify this work. The U.S. Public Health Service has formulated recommendations for economic principles to be applied in economic analyses, which should improve the rigor and comparability of future work.

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