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AMERICA

Living With

AIDS

Transforming Anger,
Fear, and Indifference
into Action

REPORT OF THE NATIONAL COMMISSION ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME

1991

CONTENTS

It's not good enough to say that we serve everyone. It's not good enough to say that our programs are open to all. If we don't specifically design our programs in such a way that they reach out into the community, that they become part of the community, and the community becomes part of them, they are not as functional as they need to be.

Coupled with our efforts to ensure access, representation, and inclusion is the essential work of stopping the progression of the disease through education and prevention activity, focusing on risk reduction and behavioral change. . . .

In communities of color, as in the majority of communities, much of the average behavior is clandestine, behind closed doors and unnamed or named differently—i.e., gay versus sex with men—so that a singular outreach strategy will only reach the most physically and obviously adverse population.

In our communities it is just as likely that we will reach at-risk people at church functions, at the barber and beauty shop, at the WICs program, in jail or work release, and topless clubs, in minor camps, in the social clubs, at the food bank, at the pow wow, or other community events, at the kind of local community gathering where people are together and where information flows.

P. CATLIN FULLWOOD
July 1990

CHAPTER TWO

PREVENTION AND EDUCATION

Until a cure or a vaccine is found, education and prevention are the only hope for altering the course of the HIV epidemic. This actually understates the importance of prevention, for prevention strategies will continue to be a key component of HIV containment far beyond the advent of successful drug treatments or vaccines. There are valuable lessons to be learned from earlier experiences with sexually transmitted diseases. Effective and inexpensive treatments for many of these diseases have long been available, yet drugs alone have not stemmed the tide of infections, especially among young people and those living in poverty. Those prior experiences are underscored by the rapid reemergence of syphilis, and it can be said with certainty that medical science alone will not be able to vanquish AIDS, even with a magic bullet.

There is an urgent need for implementation of carefully designed strategies to prevent new HIV infections (primary prevention) and to prevent disease progression for HIV-infected individuals through early diagnosis, prompt treatment, and continuing care and support (secondary and/or tertiary prevention). Educational programs are also necessary to alter the public's perceptions that HIV disease is someone else's problem. The discrimination that occurs against people with HIV disease results largely from fear and ignorance, and the best weapon against these is education.

Some of the most encouraging news thus far in the HIV epidemic comes from the success of certain health education programs that have resulted in dramatic, sustained reduction in risk behavior. There is clear evidence that prevention is possible; changes in attitudes and behavior can occur as a result of carefully tailored, targeted, and credible prevention efforts. Such success is less dramatic to the public than a laboratory breakthrough, but probably more important. This chapter considers an array of education and prevention strategies, highlights some prevention success stories, and offers recommendations to focus prevention efforts for the second decade of the epidemic. As we move into the second decade, the Commission believes poli-

cies should be developed now to address future plans for the distribution of AIDS vaccines as well as the ethical and liability issues that will arise when vaccines become available.

A DISEASE OF BEHAVIORS: CLINICAL AND EPIDEMIOLOGIC ASPECTS OF HIV

When considering prevention strategies to alter the course of the HIV epidemic it is important to keep in mind the manner in which the virus is transmitted. The limited modes of transmission of HIV have been well documented. HIV can be transmitted through sexual contact; by the sharing of contaminated injection equipment; through exposure to infected blood or blood products; and, during gestation or at birth, from an infected mother to a newborn. Breastfeeding has also been identified as a potential mode of transmission.

Understanding these modes of transmission has enabled the development of some practical strategies for use in stopping the spread of the virus. Screening of blood and voluntary deferral of blood donors at risk of HIV infection has significantly reduced the transmission of HIV through the blood supply. Sophisticated purification techniques, blood screening, and voluntary self-deferral have eliminated new HIV infections from occurring through the use of blood clotting factors to people with hemophilia. "Universal precautions" can help patients and health care workers avoid exposure to HIV. Such precautions involve the avoidance of all potentially infected blood or body fluids through barrier methods, without regard to the serostatus of patients or health care workers. The efficacy of universal precautions can be strongly inferred by a substantial drop in hepatitis B transmission (hepatitis is a hundred times more infectious than HIV). Appropriate use of condoms can decrease the risk of HIV during sexual intercourse. It is also possible to disinfect injection equipment with bleach so that the sharing of needles and syringes does not spread the virus.

In addition to the strategies available to prevent new infections, much more is now known about how to delay progression to AIDS in HIV-infected individuals. Until a few years ago, treatment regimens for HIV disease had been offered only to those exhibiting symptoms. In recent years, the clinical management of HIV disease has improved with the development of therapeutic strategies involving the use of treatments such as zidovudine (AZT) and aerosolized pentamidine for HIV-infected individuals who are still asymptomatic. This early intervention has enhanced well-being in addition to delaying the onset of AIDS, but its availability or lack thereof raises important issues of access. To bring the benefits of early intervention to people in need, additional and better coordinated services will be required—not only greater outreach, HIV testing, counseling, laboratory monitoring, medications, and primary health care, but also improved laboratory services, better

coordinated systems of care, and public and private financing strategies to pay for care.

DEVELOPING PREVENTION MESSAGES

Frank Talk About Sex and Drugs

Most of the disagreement about HIV prevention is not over goals, but over methods to achieve goals and over who should decide which methods ought to be used. As noted above, there are a number of simple, readily available technologies that will contribute significantly to reduction in the spread of HIV infection. Yet AIDS education and prevention efforts continue to be stymied by an unwillingness to talk frankly about sexual and drug use behaviors that risk the spread of HIV. Constraints on discussions of sex, whether imposed by law, political considerations, issues of morality, language, or culture, have been a substantial barrier to the creation and implementation of effective HIV prevention programs. There is a cruel irony at work here, for reticence about discussing sex has become an obstacle to the implementation of lifesaving prevention programs. This withholding of potentially lifesaving information raises serious ethical problems.

In the early years of the AIDS epidemic messages concerning HIV were couched in euphemisms. There were warnings about the danger posed by the "exchange of bodily fluids" when the phrase eluded public understanding. Generic, incomplete, and ambiguous messages such as this fostered misunderstandings about the actual dimensions of risk and the ways to avoid the threat posed by HIV disease.

Research in many areas of health education has shown that to encourage behavior change, prevention messages must be transmitted in a language and manner that can be understood by the people to whom they are directed. Those who design and implement education and prevention programs must be able to use unvarnished language and communications that are both meaningful and acceptable to the particular community or group being addressed. Where the communications are targeted to a specific group, the potential offensiveness to others to whom the message is not directed should not and need not be a barrier. Congress should remove the government restrictions that have been imposed on the use of funds for certain kinds of HIV education, services, and research.

In addition to crafting clear and explicit messages that are relevant to those at risk, a greater realism is needed in approaches to altering sexual behavior and drug use. For example, although teenagers are encouraged to delay sexual intercourse until marriage or at least until adulthood, a majority

The present situation in Puerto Rico shows the island as having such a high incidence of HIV that there exists a sense of panic about being infected. . . . Ignorance is evident at all levels of living—among employers, in public transportation, as well as funeral parlors overcharging for burials because they claim to be at risk of infection.

I feel it is urgent to bring more forceful education throughout the island to attempt to change the attitudes of panic and rejection suffered by so many patients, to become instead an environment of faith, hope and concern.

LUIS MALDONADO
November 1990

of young people have not heeded such advice, regardless of how forcefully this message has been delivered. In view of this stark and dangerous reality, advice concerning abstinence must be supplemented by frank talk about AIDS, and about how to avoid sexually transmitted diseases and unintended pregnancies. In addition, it must reach children at a young age.

> ***When you go and talk to community people about becoming part of an AIDS project, they will say, "who is in charge?" And then they will, as we say in our community, do a reading of that person.***
>
> **ALYCE GULLATTEE, M.D., F.A.P.A.**
> ***December 1990***

A similar set of problems has existed in discussions and attitudes about drug use as it relates to HIV transmission. The predominant policy approach has characterized drug use as a criminal rather than a public health problem. Here too the approach must be more than "just say no." A more realistic strategy is crucial to the prevention of HIV transmission related to drug use. Some of those at risk will be able to stop using drugs on their own, or will stop with the help of formal treatment, self-help, or "twelve-step" programs modeled on Alcoholics Anonymous. Access to drug treatment is an absolutely fundamental element of prevention in those populations. Those who find it impossible to stop using drugs, or who relapse following a period of abstinence from drugs, must be encouraged to practice safer sex and safer drug use and must be taught how to do so.

The Commission reiterates the recommendations made in its fifth interim report to the President and the Congress concerning the twin epidemics of HIV disease and substance use. The federal government should expand drug treatment so that all who apply for treatment can be accepted into treatment programs. The federal government should also continually work to improve the quality and effectiveness of drug use treatment. In addition, legal barriers to the purchase and possession of injection equipment should be removed. Legal barriers do not reduce illicit drug injection. They do, however, limit the availability of new, clean injection equipment, thereby encouraging the sharing of injection equipment, and the increase in HIV transmission.

Cultural Sensitivity and Cultural Competence

As part of the need to deal realistically with issues about sex and drugs, it is critical that these subjects be addressed in a manner that is not only culturally sensitive but also culturally competent. Especially since sex and drugs are sensitive topics, it is clear that the best prevention messages will be those developed by and for the people the messages are intended to reach, through community-based efforts at the local level. It is essential to include people living with HIV disease in HIV prevention efforts. For many communities, seeing people in education and prevention efforts who are directly affected by HIV will bring home the

reality of HIV and help overcome the denial that "this cannot happen to me or my loved ones." When gay men, women, people of color, and persons using drugs are not consulted in the design and implementation of prevention programs, programs directed toward these audiences will not be effective.

STRATEGIES IN HIV PREVENTION

The Web of Illness, Poverty, and Alienation

HIV disease is associated with a host of related health and social problems; strategies to prevent the further spread of HIV disease must take these problems into account. Other sexually transmitted diseases (e.g., syphilis, gonorrhea, chlamydia, herpes, hepatitis, and venereal warts) may act synergistically with HIV, enhancing HIV transmission or disease progression. Drug use is significantly associated with HIV disease. Injection drug use poses the most direct threat of HIV transmission when contaminated injection equipment is shared; this is a risk for intravenous users of any drug, including heroin, cocaine, and steroids. It has been less widely recognized that crack cocaine, alcohol, and other psychoactive drugs also represent serious threats when multiple sexual partners and impaired judgment about risk are involved.

From New York City to Waycross, Georgia, from San Juan, Puerto Rico, to Seattle, Washington, in hearings and site visits the Commission has seen how poverty, homelessness, lack of basic health care, lack of prevention services, and lack of drug treatment combine with the alienation experienced by gay men, poor women of color, and drug users to exacerbate the spread of the virus. A dramatic example of this is the increase in sexually transmitted diseases in many urban and rural areas in the United States.

Essential Elements of Prevention Programs

To intervene effectively in the spread of HIV it is essential to consider the broader social context of the HIV epidemic, for it involves not only individuals at risk, but also families, cultural and social groups, neighborhoods, and communities at risk of multiple problems. Although this adds to the complexity of HIV intervention, it also means that successful HIV prevention efforts will not only reduce the spread of HIV, but also are likely to have an impact on the rates of other sexually transmitted diseases, teenage pregnancy, and drug use.

> ***It's hard to educate a woman who is homeless and hungry.***
>
> SANDRA VINING-BETHEA
> *January 1991*

A mix of strategies is being used throughout the country in the design of HIV prevention programs. From grass roots efforts to federally sponsored programs, these varied approaches draw on a number of different fields, disciplines, perspectives, and experiences. The potential for success in prevention is enhanced by

government policies that are not restrictive and that create a climate in which prevention efforts can be creative, cooperative, and comprehensive. Other interventions that have helped to create a positive context for HIV prevention efforts include laws guarding confidentiality and protecting against discrimination. Without assurances that people can avail themselves of HIV prevention opportunities without risking the loss of jobs, housing, and health insurance, it is next to impossible for prevention and education services to reach those at greatest risk of HIV.

If prevention efforts are to be successful they require sustained commitment to change over the long term, rather than an expectation of short-term results. They also require support of multiple interventions and strategies, rather than investment in a single "solution." Support must be continuous and predictable. Prevention programs must be accountable, progress and results must be measurable, and training and support must be provided to those administering the programs.

Some important prevention strategies include: sex and HIV education appropriate to age levels; treatment programs for substance users; education about bleach and clean needle and syringe programs for those who are unable to stop using drugs; efforts to control sexually transmitted diseases; outreach programs to provide contraception to women of childbearing age; easily accessible HIV antibody testing and essential counseling; peer counseling; street outreach efforts; and readily available condoms supported by a social marketing program that encourages their use.

Individual and Community Approaches

Efforts designed to control HIV infection create change by intervening at many levels. Technological approaches will not work without changes in knowledge, attitudes, beliefs—and behaviors. In this second decade of the HIV epidemic, there will be an increasing need to supplement individual behavior change strategies with a concept of communitywide prevention. Similar interventions aimed at changing the norms of entire communities are among the most promising HIV prevention strategies. These interventions have proven to be effective in promoting a variety of health behaviors, such as family planning and cardiovascular risk reduction, including smoking cessation.

Communitywide models of HIV prevention make use of a mix of strategies. Communities of interest are defined by more than mere geographical proximity. Communities may be defined by:

- *common identities* such as gender, sexual orientation, race or ethnicity, language, religious affiliation, age group, or a genetic condition such as hemophilia;
- *behavior* such as same-gender sex, injection drug use or needle shar-

ing, and non-injection drug use, including alcohol use;

- *location or setting* such as hospitals, clinics, prisons, churches, work environments, and schools;
- *other circumstances* such as possible exposure to HIV infection through blood transfusions or other use of blood products.

Communitywide models are designed to utilize multiple settings, channels, and organizations in their design, implementation, and evaluation. Each community has distinct features; no two communities will be alike in their response to HIV disease, and thus the process by which a response to the HIV epidemic is mobilized in communities will also vary. Understanding more about how to respond to AIDS involves understanding and respecting what the community regards as problems and priorities, acknowledging social organization and structure, and then identifying the community's available resources and what solutions it will be ready to employ. These efforts must be supported, funded, documented, and evaluated to broaden the reach of our prevention efforts. Federal, state, and local governments should join forces with the private sector in providing long-term support to community-based organizations. As a part of this effort, the U.S. Public Health Service (PHS) should expand and promote comprehensive programs for technical assistance and capacity building for effective long-term prevention efforts.

REDUCING SEXUAL TRANSMISSION OF HIV

Substantial progress has been made in reducing sexual transmission of HIV infection among certain populations in some areas of the country. Nevertheless, sexual transmission of HIV continues to be a major route of infection. Although many more people are now aware of the types of sexual behaviors that risk the spread of HIV, the gulf between awareness of risk and long-term behavioral change can be wide. Sexual conduct is influenced by complex factors, including biological drives, religious beliefs, customs, and cultural and community norms and values. These aspects of sexual behavior make changes difficult to inculcate. Consider how difficult it is to get people to stop smoking, even when they know how dangerous it is; or how much effort it has taken to encourage people to wear seat belts, despite the manifest risks of not doing so. A psychiatrist who testified before the

"¡No mueras por ignorancia!" (Do not die because of ignorance!); "La Familia Hispana Contra el SIDA" (The Hispanic Family Against AIDS); "Informe SIDA" (AIDS Bulletin); HACER (The Hispanic AIDS Committee for Education and Resources); Proyecto "Vecino a Vecino" (Neighbor to Neighbor Project); "Iluminate. ¿Como vas a manejar? ¿Vivo o muerto?" (Know Yourself. How will you manage? Dead or Alive?); "Las Almas de Dios" (the Souls of God); "Noche de Ronda" (Night of Serenades); "La Clínica Esperanza" (Clinic of Hope); CURAS, Comunidad Unida en Respuesta al SIDA (Community United in Response to AIDS).

These and many more are the collective response of the Latino/ Hispanic community's fight against AIDS in this country.

ADOLFO MATA
March 1991

Commission made a telling comparison: "We are essentially asking people to go on a diet and never cheat for their entire life. Unlike a diet, cheating may be lethal."

Same-Gender Transmission

Homosexual and bisexual men still bear much of the burden of HIV disease in the United States across all racial and ethnic groups. In cities with large gay communities, such as San Francisco and New York, a substantial portion of gay men are infected with HIV. The validity of programs of prevention is dramatically underscored by studies in the last several years of white gay men in urban epicenters of the HIV epidemic. Sustained changes in sexual behavior have been accompanied by a marked lowering of the rate of incidence of new infections. Interpretation of these trends is further supported by stable or falling rates of sexually transmitted diseases.

A dramatic change in peer behavioral norms among gay men is one of the heartening stories of the HIV epidemic. Early in the epidemic, programs were established to impart information, to help motivate change, and to bolster skills necessary to change behavior, such as ways to negotiate safer sex. Many of these programs came from within the gay community and relied to a large extent on volunteers, as many governmental agencies were not confronting the epidemic. The result of these programs was that many gay men increased condom use, adopted safer sex practices, and reduced the number of their sexual partners.

Although many gay men have made remarkable changes in sexual behavior, these changes should not be taken as evidence that the job of education and prevention *has* been done, but rather that it *can* be done. There are many men who engage in same-gender sex but do not perceive of themselves as being gay or as belonging to any gay social or political community. These men are particularly difficult to reach with gay-specific HIV prevention messages. Targeted messages about behavior change may have passed them by. In addition, as the epidemic matures, sustained efforts will be necessary to prevent "relapse" among gay men who have made changes in their sexual behavior. More attention to the relationship between alcohol and drug use and sexual behavior is warranted, as those who combine sex with alcohol and other drugs are more likely to engage in sexual activities that carry a high risk of HIV transmission.

Gay and bisexual men are the largest segment of people with AIDS

What honor can there be in being a hero in a losing battle? History teaches us that those who exhibit valor on behalf of the conquered become forgotten. There's an increasingly large body of evidence that suggests that those of us who are ourselves infected with the HIV virus are already forgotten, especially if we are black and gay or bisexual.

PHILL WILSON
January 1990

among blacks and Hispanics (36 and 40 percent of cumulative cases, respectively, as of June 1991). A total of 28 percent of gay and bisexual men with AIDS are black or Hispanic. Despite these realities, epidemiologic and behavioral studies in HIV disease had until recently focused overwhelmingly on white gay men. Gay men of color may face special risk-reduction challenges. More must be done to reach out to these men and empower them through prevention efforts.

Women who have sex with other women have been neglected in HIV prevention efforts. The lack of attention to this group of women is due in part to a tendency toward rigid categorization that belies the true variety of human sexual experience. Lesbians are still viewed by many in terms of their status as members of a group rather than the behaviors they may practice and thus are often overlooked in prevention efforts. Many of these women may have a false sense of security about their risk of HIV infection and consequently neglect to practice safer sex habits. Lesbians must be given information about how to reduce the risk of HIV transmission and must be encouraged to practice safer sex with both female and male sexual partners and to use safe injection procedures if they use injection drugs.

Adolescents who are just entering a phase of sexual experimentation or who are beginning to express their sexual identity may be at special risk for HIV infection. The well-known tendency of teenagers to deny risk is abetted in the case of gay youth by the lengthy incubation period of the AIDS virus—as many as five to ten years may pass between infection with HIV and development of clinical symptoms. Approximately 20 percent of AIDS cases have occurred among individuals aged 20 to 29; most of these people were probably infected during their teenage years. Gay males in their teens and twenties outside urban epicenters of HIV are significantly more likely than older men to engage in unprotected anal intercourse and to do so with more partners, according to current studies reviewed by the Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences of the National Research Council. Young gay men often wrongly perceive the risk to be solely from older men, deriving a false sense of security from having sex with other young men who appear healthy, but who actually may be HIV infected.

Heterosexual Transmission

Over the past few years concern over AIDS cases in the United States attributed to heterosexual contact has grown. Cumulatively, 6 percent of all AIDS cases in the United States are due to heterosexual contact. In this exposure category, women are at greater risk than men of acquiring infection through heterosexual contact. Thirty-three percent of all

Thirty-three percent of all women with AIDS as opposed to 2 percent of all men with AIDS report exposure through heterosexual contact.

I am twenty-one years old. I have hemophilia and am HIV positive. I found out my HIV status when I was fourteen—when they thought it could mean I was immune. It didn't really matter what they thought then anyway. Death means absolutely nothing to a fourteen-year-old. I thought I was immortal until just about a year ago when my girlfriend at the time and I were going to find out the results of her first AIDS test. Meanwhile, most of my friends still think they are immortal. This is one of the basic tricky aspects of AIDS for the adolescent and the young adult. It is extremely hard to have a mid-life crisis and acknowledge the fact that you are going to die when life has just begun. The other is the fact that this acknowledgement of death comes through something that is the reaffirmation of life and love—sex.

T. H.
April 1991

women with AIDS as opposed to 2 percent of all men with AIDS report exposure through heterosexual contact. It is important to note that a majority of female heterosexual cases are related to unprotected sex with an HIV-positive intravenous drug user. Women of color have been particularly heavily affected.

These statistics are particularly troubling because many women believe they are not at risk and do not need to practice safer sex or change potentially dangerous behaviors. Prevention messages are not effectively reaching large populations of women. Much of the attention women have received in the HIV epidemic has been related to the potential for the spread of HIV to their sexual partners or offspring; women are frequently characterized, explicitly or implicitly, as "vessels of infection" or as "vectors of perinatal transmission." Women need attention in their own right, not only in the development and evaluation of HIV prevention strategies, but in all aspects of HIV policy development.

Many prevention messages have not been grounded in the realities of women's lives. Not surprisingly, such messages have not been very effective. Perhaps the most unrealistic prevention message for women is the nearly exclusive focus on the use of condoms, advice that is naive regarding anatomy, gender roles, and power relationships. The emphasis on condoms grew out of the early years of the HIV epidemic when sex between men was a predominate concern. As more knowledge has been gained about the epidemic, the need for alternative prevention methods has been clearly indicated. Condom use requires the active involvement of the male partner, and the woman must secure his cooperation or convince him to terminate the sexual interaction if he refuses. The use of condoms may be complicated by the perception that their use is an admission of infidelity, hence threatening relationships of long standing. In fact, many men report using condoms "on the side," but not in their primary relationships.

That condom use is inherently limited as a method for preventing the heterosexual spread of AIDS does not imply that attempts to encourage their use should be abandoned, but rather that such efforts should be redoubled. The United States has yet to embark on campaigns such as have been undertaken in other countries to foster fundamental changes in social attitudes about condoms, through advertising, social marketing, and intensive outreach and reinforcement strategies.

Across categories of exposure, individuals for whom condoms might reduce risk report only limited consistent use of them. Condoms must be made more widely available and information on how they can be effectively used must be provided. Further, their use must be promoted through sophisticated social marketing strategies. The de facto ban on network television advertising of condoms continues to impede their social acceptability. These and other impediments to the use of condoms should be recognized and addressed. More behavioral research is needed to develop methods of HIV prevention during sexual contact that are acceptable to both women and men.

While attempts to promote greater use of condoms to reduce transmission of HIV should continue, it is equally important that research funds and personnel be devoted to the exploration of alternative methods of preventing HIV transmission. Increased efforts are necessary to develop a wider array of chemical and physical barriers to block vaginal HIV transmission that do not depend entirely on the male partner's cooperation. These include gels, suppositories, or sponges that might be used before or after intercourse. More research is needed on chemicals that kill viruses (virucides). A female condom is also in development. The diaphragm should be evaluated in terms of its potential role in HIV prophylaxis.

In considering alternatives to condoms that might be more relevant for women, it is important to consider not only *efficacy* (the probability of preventing HIV transmission given optimal or correct use of a prevention technique or device), but also *effectiveness* (efficacy plus the extent to which the device or technique will be used correctly and therefore contribute to a slowing of the epidemic). Even surefire methods of prevention are worthless unless people are willing to use them.

Teenagers tend to deny risk. Yet, even when they recognize the risks of HIV, many adolescents still feel they are invincible or discount the risk of HIV because other risks in their environment are perceived as greater and more immediate. Adolescents are at risk, not only from their own perceptions of lack of risk, but also because adults often ignore the special needs of adolescents or deny that adolescents are sexually active.

Abstinence is an efficacious means of eliminating the risk of sexual transmission of HIV. However, although many young people have been encouraged to delay intercourse until marriage or adulthood, some teenagers will choose to begin sexual behaviors during adolescence. In fact, studies in 1988 revealed that by age 15,

The hopelessness that is connected with adult life for young minority people is a future of which they are aware. If we don't change the fact that they have no hopeful future, I'm not sure we can take the pressure off the wish to find whatever joyous escape exists in the present.

MINDY FULLILOVE, M.D.
March 1991

27 percent of girls and 33 percent of boys were sexually active. Half of girls had had sex by age 17 and half of boys by age 16; three out of four unmarried 19-year-old women and five out of six unmarried 19-year-old men had had sexual intercourse.

Moreover, unprotected sexual activity is clearly occurring among teen- agers. Other clear evidence for adolescent sexual behavior is found in the high rates of sexually transmitted diseases among sexually active adolescents and the fact that approximately one million teenage girls become pregnant each year. According to a study conducted by the National Research Council, entitled *Risking the Future*, more than 400,000 of these pregnancies occurred in young women 15–17 years of age. Pregnancy still remains the focus of many health and sex education programs. If birth control is the sole objective, an oral contraceptive may be used instead of a barrier method that would also help to prevent HIV and sexually transmitted diseases. Some young women practice anal or oral sex as a birth control method, which may pose increased risks for transmission of HIV. Education messages to young women and men must be twofold, teaching ways to prevent both pregnancy and disease.

We have over twenty identified Asian/Pacific communities here in southern California. We speak different languages. We come from very different cultures, ethnic backgrounds. Language is a barrier for us, not just English. Along with language, we have cultural barriers—gan-barr, the barrier of denial, bringing shame to the family. Homophobia and/or homoignorance. These are all issues and barriers that exist within our community.

DEAN GOISHI
January 1990

Adolescents need clear, realistic, unequivocal prevention messages about the risks of HIV transmission associated with unprotected sexual activity, sharing of injection equipment, and sexual activity in conjunction with substance use. Adolescents must also be provided with the tools necessary to engage in safe behaviors. Adults must use their knowledge to impart information despite their own embarrassment or reluctance to discuss sex.

Although many adolescents practice risk behaviors, some have a more difficult time than others finding information or avoiding risk behaviors. These adolescents need targeted programs. Some studies have shown African-Americans, Hispanics, and other youth from communities of color to be less aware of what places them at risk for HIV transmission than white youth. Special attention should be given to these communities. Young people who are infected with the virus need counseling and education to deal with the difficulties of living with HIV disease.

Sexual Transmission Related to Substance Use

Sexual transmission of HIV related to substance use concerns sexually active individuals, whether gay, lesbian, or heterosexual, whether adult or adolescent. Injection drug use is clearly linked to sexual transmission of HIV. It is less well known that sexual activity in conjunction with the use of other

psychoactive substances, including alcohol and crack cocaine, poses a substantial risk. Sexual transmission with regard to substance use occurs when judgment about safer sex is impaired as well as when sex is traded for drugs.

Prevention messages about sexual behavior as well as drug use may be effectively conveyed in drug treatment programs. Unfortunately, drug treatment opportunities, deficient for men, are in even shorter supply for women. This problem is in part a continuation of prior inequities, for women have traditionally had difficulty gaining access to drug treatment facilities, which for the most part have been oriented toward the needs of men. Women with children and pregnant women who use drugs often have special difficulty finding drug treatment that meets their needs. Women in need of treatment are often single parents who attend to their children's needs before their own. Even when pregnant drug users are accepted into treatment, a significant opportunity for intervention may be missed, since there are often no provisions for prenatal care.

Sexual partners of individuals who use intravenous drugs are often unaware of the risks they face, either because their partner's drug use is covert, or part of the past, or because they are unaware of the associated risks of HIV. Those who are aware of the risks may still face difficulty in seeking counseling for risk reduction. Thus, the simple steps that must be taken to prevent AIDS, such as condom use, may not be so simple after all.

Adolescents may be at heightened risk for transmission through sexual activity in conjunction with the use of substances other than injection drugs. While some studies indicate that adolescents may avoid intravenous drug use, the use of alcohol and the growing use (especially in low-income urban communities) of crack cocaine places these individuals at increased risk. It is extremely important, therefore, not to assume that intravenous drug use is the only link between drugs and sexual transmission.

REDUCING HIV TRANSMISSION RELATED TO INTRAVENOUS DRUG USE

Successful and sustained risk reduction among injection drug users is vital to slowing the spread of HIV infection. Injection drug users place themselves at risk through a variety of behaviors, and may spread the virus not only to their needle-sharing peers, but also to their sexual partners and at birth to their offspring. Hence, any potentially successful program must address drug use and sexual behaviors simultaneously. It is also important to provide prevention education to all those who engage in the risk behavior of sharing injection equipment, including athletes who inject steroids and individuals who inject vitamins and medications.

Although there is a commonly held misconception that drug users in the throes of addiction are impervious to messages about the risk of HIV trans-

mission, the evidence suggests otherwise. Drug users know a great deal about how HIV is transmitted and are willing to make the changes necessary to reduce risk of transmission when encouraged to do so. There is evidence that HIV prevention strategies targeting injection drug users can result in decreased needle sharing, increased needle cleaning, increased demand for sterile needles on the street, and stable or declining seroprevalence rates among drug users. In addition, when such HIV-related interventions are offered, there is often an increased demand both for treatment for addiction and for primary care.

Some consistent messages have emerged from studies of the impact of HIV on drug use behaviors. Most drug users report changing their behavior in response to AIDS. There is no single method of reducing HIV risks that will work for all drug users; prevention strategies must encourage both cessation of use and the adoption of safer injection practices for those who continue use. Finally, more drug users have reported changes in drug use practices than changes in sexual behaviors, and yet, of course, both are essential. Thus, renewed efforts to encourage behavioral changes related to both sex and drug use are necessary.

HIV associated with drug use has potential for extremely rapid spread. Some cities have already experienced this, with up to 50 percent of intravenous drug users HIV seropositive. In other cities with large populations of intravenous drug users, HIV seroprevalence remains at much lower levels. The geographic variation in HIV seroprevalence among intravenous drug users underscores the opportunities for heading off the spread of HIV disease. HIV prevention strategies targeting injection drug users now include clinic-based interventions, street outreach projects, community-based information and awareness campaigns, and both publicly supported and unsanctioned needle exchange programs.

As the Commission noted in its recent report, *The Twin Epidemics of Substance Use and HIV,* the unmet need for treatment on demand is critical. In cities hard hit by both drug use and HIV disease the situation is extremely serious. New York City, for example, has an estimated 200,000 intravenous drug users, approximately half of whom are HIV positive. Yet New York has only 38,000 publicly funded drug treatment slots. Outreach efforts have had the positive side effect of referring individuals to treatment programs, but these gains will be lost if there are not enough treatment slots available.

Among the most important AIDS prevention efforts are those aimed at

What do we do now? We do what many cities have been doing for several years now. We take it to the street. We take treatment to the user. We take intervention to the user. We take education to the user. We take prevention to the children and families. Prevention is all of the above. We take hope to people who have no hope. We become advocates. We become transportation. We bring food and clothing to those who have no food and clothing. We let the user, the addict, and the persons living with HIV and AIDS know that we truly care. We open doors for them that previously were shut—treatment doors, emergency care doors, medical care doors, and whatever doors remain locked.

EDMUND BACA
January 1991

encouraging injection drug users to adopt safer injection practices, either by using bleach or by participating in needle exchange and distribution programs. These programs have frequently been delayed or blocked by political and community opposition and by laws that make possession of drug injection equipment a criminal offense. In some localities, criminal justice officials have looked the other way as local public health officials and activists have mounted needle exchange and distribution programs. On occasion, local prevention activists charged with crimes for distributing clean needles have defended their actions in court, claiming that any violations of law in distributing clean needles were justified by the need to save lives. This was borne out in the recent decision of a Manhattan judge who overturned criminal charges against AIDS activists engaged in distributing sterile needles by stating, "The nature of the crisis facing the city, coupled with the medical evidence offered, warranted the defendants' action." Courts in Massachussetts and California have also failed to convict people conducting needle exchange programs.

Fears that needle and syringe exchange and distribution programs might encourage drug use and create a new class of drug injectors have not materialized. Where such programs have been operating, they have provided a means of encouraging injection drug users to join treatment programs. Needle and syringe distribution programs deserve further experimentation, and laws and regulations that block implementation and study of such programs should be repealed.

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REDUCING PERINATAL TRANSMISSION

HIV prevention strategies and messages for women who wish to consider becoming pregnant may have to be quite different than those for women who are willing to delay having children. Issues of disease prevention are often conflated with questions of pregnancy and reproductive choice. A number of steps aimed at preventing pregnancies, such as vasectomies, intrauterine devices, and oral contraceptives, may have little or no impact on interrupting the spread of HIV disease.

In recent years there has been much debate about whether HIV antibody testing of pregnant women or newborns ought to be mandatory, routine, or merely available. The backdrop against which these debates are taking place is a set of clinical studies that reveal that transmission of the virus from HIV-positive mothers to newborn children is less than previously thought, approximately 30 percent or less. HIV antibody testing of newborns only definitively establishes whether the mothers are HIV positive. Newborns who test HIV positive may or may not be infected. Some will test positive only because of the presence of maternal antibodies that will eventually disappear. Debates have centered on whether testing or screening ought to involve all pregnant women or merely those at "high risk" of HIV and the extent to which counseling ought to be

directive in discouraging HIV-infected women from becoming pregnant or bearing children. HIV antibody screening of pregnant women and newborns raises profound moral, legal, and policy issues that are dealt with at considerable length in recent reports on the subject by the Institute of Medicine (1991) and other policy groups.

The medium is the message. You can't have safe sex at Cabrini Green Projects. It's not a safe place.

MICHAEL JAMES
March 1991

All women of childbearing years who are considering pregnancy or are pregnant must be apprised of all the options available to them—they must be informed of their options but not coerced into any particular decision. Just as much of the advice to date for women about how to prevent the sexual transmission of HIV may have been of little relevance to their lives, there is a growing realization that blanket advice for HIV-positive women to avoid becoming pregnant may not be appropriate. As noted in a report by the Institute of Medicine, *HIV Screening of Pregnant Women and Newborns*, ". . . limited studies to date offer little evidence to suggest that knowledge of HIV infection status significantly affects women's decisions regarding continuation of a pregnancy or future childbearing." For many women, having children is a large part of being a woman; thus, fully informed women may decide that it is worth running the risk of perinatal transmission to give birth.

RESEARCH AND EVALUATION REGARDING PREVENTION PROGRAMS

During the first decade of the HIV epidemic the need for epidemiologic and behavioral research was recognized. The published literature that resulted consists primarily of a mosaic of small-scale studies, examples of behavioral interventions demonstrated to be effective either in reducing new HIV infections or in making substantial modifications to high-risk behaviors in narrowly defined populations. In the earliest phases of the epidemic, a great deal was learned about appropriate prevention strategies among those identified to be at risk, especially white, self-identified gay men in urban areas.

There remains, however, a lack of knowledge in several areas crucial to education and prevention—sexual and other behavior patterns in people of varied cultural, racial, and ethnic groups; frequency of different types of sexual behavior among adolescents or adults; family or community approaches to prevention; technological approaches to prevention, including female-based research on virucides and barrier methods of prevention; large-scale studies of needle exchange programs in the United States; and innovative approaches in prevention, including communitywide approaches.

Greater priority and funding should be given to behavioral, social

science, and health services research. Social marketing and communications research are also necessary to find out whether national mass media campaigns, such as CDC's "America Responds to AIDS" campaign are effective, among what groups, and for what purposes. The number of racial and ethnic minority health professionals must be increased. Every effort must be made to identify, nurture, and support researchers indigenous to the community.

It is critical that researchers clearly establish what does and does not work in prevention. The cost of not knowing will be measured not only in dollars spent and opportunities missed, but also in lives lost. Future prevention efforts are greatly hindered by insufficient evaluation of HIV prevention services and programs within CDC and other federal agencies, as well as within local communities. The National Research Council (NRC) has proposed an evaluation strategy based on three key questions:

1. What interventions are actually delivered?
2. Do the interventions make a difference?
3. What interventions or variations work better?

As NRC notes, "The evaluation of AIDS intervention programs is not an easy task: it will take time, and it will also require a long-term commitment of effort and resources. . . . The nature of the HIV/AIDS epidemic demands an unwavering commitment to prevention programs, and ongoing prevention programs require a similar commitment to their evaluation." NRC recommends a full complement of evaluation research, encompassing formative, process, and outcome evaluation (NRC, 1991).

The Commission agrees that evaluation is needed at every step of development and implementation of HIV prevention programs. Participatory evaluation—which includes groups targeted by the programs and groups providing the programs, as well as funding agencies—is a critical aspect of evaluation that has been frequently overlooked. Communities should not be viewed by academic evaluators as a place for experimentation without consultation or collaboration. There is a need for greater collaboration among federal agencies, especially CDC and the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), related to research and evaluation strategies and HIV prevention. The federal behavioral research establishment has an important role to play in "meta analysis"—the collation and comparison of various small-scale research studies. It can also provide mechanisms so that those responsible for the development of prevention programs can be kept abreast of the latest developments.

But even the best efforts to increase the knowledge base and to improve information dissemination strategies will be for naught if the knowledge gained is not effectively applied.

Unfortunately, the findings of research on HIV education and behavioral interventions are only partially applied because of restrictions placed on prevention messages by the U.S. Congress. In the area of prevention, it is also important that the United States consider adopting successful prevention models developed in other countries. Examples would include sexual education programs in Scandinavia that have led to low rates of sexually transmitted diseases and unintended pregnancies (though rates of sexual activity are comparable to the United States) and programs of over-the-counter sales of needles and needle exchanges throughout Europe and Australia that have reduced needle sharing without leading to increased intravenous drug use.

A COMPREHENSIVE NATIONAL HIV PREVENTION INITIATIVE

The federal government should establish a comprehensive national HIV prevention initiative that integrates the approaches of federal, state, county, and municipal government; community-based organizations; the private sector; and affected populations. This strategy should ensure both central coordination and local autonomy. At the federal level, a plan should be established within the Public Health Service and across other federal agencies to coordinate development of effective HIV prevention programs, rather than allowing each agency or institute to pursue potentially idiosyncratic activities. Emphasis should be placed on linking health care and prevention efforts. The Commission stresses the urgent need for implementation of carefully designed strategies to prevent new HIV infections and to prevent disease progression for HIV-infected individuals through early diagnosis, prompt treatment, and continuing care and support. Offering advice about changes in behavior and making referrals to education, counseling, and prevention services is a critical aspect of delivering HIV care.

Although some states and localities have built infrastructures to enable them to mount effective primary and secondary prevention programs, others have not. Community-based organizations, often the heart of primary prevention efforts, are even less likely to have the strong administrative and fiscal structures that would ensure that their programs remain sound. Many community-based organizations have relied upon seed money or demonstration grants from governmental or private foundation sources. The fragility of funding streams has made it difficult to plan, implement, and evaluate programs, especially for newer groups in minority communities. Rigid requirements hinder attempts to develop and sustain meaningful programs. Delayed reimbursements jeopardize the very existence of community-based organizations,

which are a critical element of HIV prevention activities nationwide.

Communities must find better ways to mobilize, plan, design, and implement comprehensive communitywide HIV prevention efforts. Public health departments, community-based organizations, and affected populations must be able to work through and resolve conflicts. CDC, the Health Resources and Services Administration, ADAMHA, states, county and municipal governments, and community-based organizations need flexibility in funding. The concept of HIV care consortia, as in the Ryan White CARE Act, merits consideration in HIV prevention efforts. The National Institute of Mental Health's model for mobilizing communities around issues related to the severely mentally ill may be another potential model.

The primary and secondary prevention of HIV disease deserves a place on everyone's agenda. It is within our capacity as individuals, as members of various communities, and as a nation to halt the further spread of HIV and to extend and enhance the quality of life for those already infected. We must learn to draw upon our diversity in order to bring people together to confront the challenges posed by HIV.

RECOMMENDATIONS

1. **The federal government should establish a comprehensive national HIV prevention initiative.**
   This initiative should be authorized by Congress and developed by the Department of Health and Human Services. It should provide flexible resources to state and local government and other public or private nonprofit entities for communitywide HIV prevention efforts. It must also include input from individuals who have expertise through experience, education, or training. The prevention initiative is an essential component of a national HIV plan.

2. **Greater priority and funding should be given to behavioral, social science, and health services research.**
   Behavioral, social science, and health services research are currently grossly underfunded. The Commission believes there must be a more appropriate balance of funding between these areas of study and biomedical research.

3. **Congress should remove the government restrictions that have been imposed on the use of funds for certain kinds of HIV education, services, and research.**
   Government restrictions on certain HIV programs and on behavior-oriented research studies impede the fight against HIV disease. HIV prevention programs and research into sexual and drug using behaviors must be conducted and evaluated. Results from these and other health promotion and disease prevention efforts must be shared and rapidly incorporated into HIV prevention and education strategies.

4. **The U.S. Public Health Service should expand and promote comprehensive programs for technical assistance and capacity building for effective long-term prevention efforts.**

5. **Federal, state, and local governments should join forces with the private sector in providing long-term support to community-based organizations.**
   Community-based efforts are now and will continue to be an integral part of any HIV prevention strategy. The role of people with HIV disease must be recognized, encouraged, and supported. In designing services, community-based organizations and their programs must be accountable, yet they must be afforded sufficient flexibility to implement programs that will best serve communities in need.

6. **Policies should be developed now to address future plans for the distribution of AIDS vaccines and the ethical and liability issues that will arise when vaccines become available.**

7. **The federal government should expand drug abuse treatment so that all who apply for treatment can be accepted into treatment programs. The federal government should also continually work to improve the quality and effectiveness of drug abuse treatment.**

8. **Legal barriers to the purchase and possession of injection equipment should be removed.**
   Legal barriers do not reduce illicit drug injection. They do, however, limit the availability of new, clean injection equipment, thereby encouraging the sharing of injection equipment, and the increase in HIV transmission.