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Confronting AIDS

Update 1988

Institute of Medicine
National Academy of Sciences

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Committee for the Oversight of AIDS Activities

STAFF

CONSULTANTS

Preface

Twenty months ago, in October 1986, the Institute of Medicine/National Academy of Sciences (IOM/NAS) issued *Confronting AIDS: Directions for Public Health, Health Care, and Research*. That report described what was known then about the acquired immune deficiency syndrome (AIDS). It contained the information on which the IOM/NAS Committee on a National Strategy for AIDS based its conclusions and recommendations. Appendix A in this volume is the summary and recommendations from that report.

In March 1987, IOM/NAS created a new committee, the AIDS Activities Oversight Committee, and charged it to monitor and assess the nation's response to the problems raised by AIDS in matters of public health, health care, and research. The committee was also asked to coordinate and oversee studies and activities concerning AIDS throughout the National Academy of Sciences complex.

One of the committee's first undertakings was to review *Confronting AIDS*, a year and a half later, with an eye toward assessing the nation's progress against AIDS and appraising the quality and extent of its responses. To supplement its expertise, the committee identified approximately 60 correspondents; these included experts in the fields of molecular biology, immunology, virology, drug and vaccine development, clinical medicine, epidemiology, public health, international health, infectious diseases, ethics, law, education, social sciences, the history of science, and other disciplines, as well as administrators of the major federal agencies concerned with AIDS and some state and local officials. These correspondents were asked to prepare papers for the committee describing progress and events in their

fields since the fall of 1986. Appendix C is a list of the correspondents from whom material was received.

This report presents the committee's findings and the recommendations that arose from them. It should be viewed as an update of and a supplement to *Confronting AIDS;* it makes no attempt to duplicate the breadth and depth of information available in the original report. The preponderance of the factual material in *Confronting AIDS* remains accurate as of May 1988. For a basic understanding of the scientific knowledge that underlies both recent advances and the current recommendations, the committee refers the reader to that volume.

This update highlights new information or events that have given rise to the need for new directions; it also focuses on recommendations from the earlier report that deserve reemphasis. Chapters tend to vary in length and in the depth of their analysis, reflecting the reality that more or less progress has occurred in different areas and also the committee's intent to provide useful information to a varied audience of laypersons, scientists, and policymakers. The committee plans to address some areas more fully in the future; the U.S. role in combating the global epidemic, for example, awaits further study.

It is now clear that the "AIDS epidemic" is really an epidemic of HIV infection, and when referring to the epidemic in general, we use the terms interchangeably. When we discuss target populations for intervention, however, we distinguish among asymptomatic infected persons, symptomatic individuals, or people with AIDS as defined for surveillance purposes by the Centers for Disease Control (see Appendix B). As is true for any new disease, we expect that terminology will continue to evolve as our understanding increases.

Finally, like its predecessor body, the AIDS Oversight Committee was continually aware that it was assessing a "moving target." As new developments occur and new knowledge is acquired, the committee will pause again for reflection and evaluation.

ACKNOWLEDGMENTS

The committee wishes to thank the many persons who took time from their activities to assess the current status of their fields for the purposes of this report. Thanks are also due to the members of the AIDS Oversight Committee, all of whom made exceptional efforts to fulfill the requirements of the update. Finally, I wish to acknowledge the remarkable contribution and tireless assistance of the IOM/NAS staff headed by Robin Weiss.

THEODORE COOPER
Chairman of the Board and
Chief Executive Officer
The Upjohn Company

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Confronting AIDS

Update 1988

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INTRODUCTION

The past four decades have witnessed unprecedented success in controlling infectious diseases, an achievement that has created great confidence in medicine's ability to conquer sickness. Yet in only a few years, the epidemic of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) has shaken this confidence and revived fears at least as old as the medieval plagues.

Indeed, the plagues and more recent pestilences offer parallels to the AIDS epidemic. Both the bubonic plague and, in a period closer to our own, syphilis have evoked many of the same questions we now grapple with: tensions between individual liberties and the public good, the responsibilities of physicians toward their patients, the attribution of moral meaning to biological phenomena, the quest for a "magic bullet" cure, and controversy about the proper educational approach to changing the behavior that spreads the infection.

Epidemics of fatal infectious diseases are not unique in human history, but each is a unique event in its own time. Furthermore, there are important differences between AIDS and past epidemics, and between AIDS and other diseases of our own time that exact a heavy human toll. **The committee believes** that AIDS is a special case among current diseases. It is a fatal, infectious disease for which there is now no cure, and its sufferers appear to remain infectious for life. HIV infection and AIDS strike primarily the most productive group of society—young

adults. Attempts to control the disease by traditional public health measures are complicated by the fact that AIDS first occurred in already stigmatized groups—homosexual men and intravenous (IV) drug abusers—and the social response to the disease has been confounded by moralistic assignments of blame. A further compelling reason to direct special attention toward AIDS is that it is preventable by modifying the behavior that brings people into contact with the virus.

Coping with AIDS highlights many of the deficiencies in our social, biomedical, and health care systems. Just as the results of our experiences with other diseases have equipped us to address the challenge of HIV infection and AIDS, so will the solutions to the AIDS crisis produce benefits in diverse and possibly unforeseen areas that may well be applicable to other illnesses.

HIV INFECTION AND ITS EPIDEMIOLOGY

New information about HIV infection and its epidemiology has emerged either to confirm or alter earlier impressions of the disease. One question that has been resolved is the causative agent of AIDS. HIV and AIDS have been so thoroughly linked in time, place, and population group as to eliminate doubt that the virus produces the disease. **The committee believes** that the evidence that HIV causes AIDS is scientifically conclusive.

The observation of HIV-infected persons over longer periods of time has revealed that a larger and larger proportion of them develops AIDS. Current information suggests that the vast majority of persons who are seropositive—that is, carrying antibodies—for HIV will eventually progress to AIDS if no treatment is found to slow or halt the progression of the infection. A group of homosexual men in San Francisco has been studied longest because samples of their blood were available from earlier hepatitis vaccine research. After 8½ years, more than 40 percent of the HIV-infected members of the group have developed AIDS. Some analysts believe that virtually all infected persons will eventually develop AIDS.

The Spectrum of HIV Infection

HIV infection manifests itself in a variety of conditions, which complicates efforts to define the disease. Yet a definition is crucial to fighting a disease, beginning with the need simply to monitor its spread. The federal Centers for Disease Control (CDC) formulated an initial definition of AIDS in 1982 for surveillance purposes that relied on the presence of opportunistic infections and malignancies. In 1987 the definition was

revised to incorporate two other syndromes: dementia and wasting syndrome. It has long been apparent, however, that many HIV-infected persons suffer from clinical syndromes and laboratory test abnormalities that signal the presence of disease but do not meet CDC criteria for AIDS. Earlier in the epidemic, certain clusters of symptoms were said to belong to an AIDS-related complex (ARC), which was incorporated in a CDC definition (but never used for case reporting). By now, however, **the committee believes** that the term ARC is no longer useful, either from a clinical or a public health perspective, and that HIV infection itself should be considered a disease.

Viewing HIV infection as a disease is important because it may eventually be amenable to treatment and patients will need to be diagnosed and treated as early as possible. Clinically, it is more accurate to describe HIV infection as a continuum of conditions associated with immune dysfunction. From a public health perspective the important event is infection rather than full-blown disease because even asymptomatic infected persons are capable of infecting others.

Modes and Efficiencies of HIV Transmission

Evidence continues to build that HIV transmission occurs only through sexual contact, the use of contaminated needles or syringes, exposure to infected blood or blood products, and transplanted tissue or organs from an infected donor. The virus may also be transmitted from mother to child either across the placenta or during delivery.

The virus can be transmitted in either direction between men and women. Heterosexual spread in the United States thus far has largely occurred when one partner was infected by a nonsexual route, usually by contaminated drug injection equipment. Heterosexual transmission of HIV has not shown the rapid increases that once were predicted, but the possibilities of such increases remain. In parts of Africa, heterosexual HIV transmission is great enough to sustain the disease in an epidemic status.

The modes of HIV transmission are well documented. What is not as clear is how easily or how "efficiently" the virus is transmitted by the various routes if a person is exposed. Comparisons are difficult because the denominators are so different—the risk of infection for each act of homosexual intercourse, for each use of a contaminated needle or syringe, for each blood transfusion, and so forth. However, it can be concluded that perinatal transmission and transfusion of infected blood are highly efficient vehicles for HIV spread. Studies of infected IV drug abusers also report high rates of infection for this group, suggesting that sharing contaminated needles and syringes, combined with frequent

injections, carries a high risk of infection. Sexual partners of IV drug abusers appear to have a greater risk of becoming infected than the sexual partners of persons infected by other routes; what is not known is whether these sexual partners are infected by heterosexual transmission of the virus or by the unacknowledged sharing of contaminated needles and syringes. Sexual partners of persons infected by routes other than IV drug abuse have much lower risks of infection, as do health care workers who receive an accidental needle puncture.

Prevalence and Incidence of Infection in the United States

A report by CDC in November 1987 indicated that HIV infection remains highest in those risk groups that account for the majority of reported AIDS cases. Among homosexual and bisexual men, most prevalence estimates fall between 20 and 50 percent. However, these figures probably overestimate the true HIV prevalence in this group because they are based on surveys that used self-selected samples (i.e., the survey respondents were either seeking medical attention for sexually transmitted diseases or were concerned that their past or present sexual behavior had placed them at risk). The prevalence of HIV infection was high (50 to 60 percent) among IV drug abusers in New York City and northern New Jersey but much lower (less than 5 percent) in other areas of the country. Hemophiliacs who received blood clotting factor before 1985 show a prevalence of infection of 15 to 90 percent, depending on the type of hemophilia they have and the amount of clotting factor they received.

Data on the incidence of new infections are more difficult to obtain than are prevalence data, but they are crucial for longer term projections of the epidemic's course. Group studies of homosexual men indicate a lower HIV incidence rate during 1985–1987 than in the earlier part of the decade. Tightened procedures for blood donation and screening have greatly reduced new infections among hemophiliacs and transfusion recipients since 1985. In contrast, HIV incidence seems to be rising among New York City and San Francisco IV drug abusers.

CDC has scaled back somewhat its estimate of the number of infected people in the United States. In 1986 the estimate was 1 to 1.5 million; in late 1987 it was 945,000 to 1.4 million—a change occasioned by new information on the size of the groups that were known to be infected and new seroprevalence data for these groups.

By mid-May 1988, the AIDS cases reported to CDC totaled 62,200, a cumulative total more than two-and-a-half times that of September 1986. The demography of AIDS includes its rise to become the leading cause of death in New York City among men aged 25 to 44 and women aged 25 to

34. In 1986, New York City and San Francisco accounted for about 40 percent of all AIDS cases in the nation; by 1991 it is estimated that they will account for only 20 percent, suggesting that other localities may soon be forced to cope with the epidemic's burdens.

Epidemiological studies yielded many of the estimates described above, but the imprecision of those figures and others about prevalence, incidence, modes and efficiencies of transmission, and other crucial information bespeaks the need for more facts. **The committee therefore strongly urges** continued epidemiological research in support of appropriate prevention and control measures.

UNDERSTANDING THE EPIDEMIC'S COURSE

To alter the course of the HIV epidemic, planners must estimate, as early and as precisely as possible, how it will progress. Such predictions, like any forecasts, have to be based on the data that are available, however incomplete they may be. The techniques used to bridge the gaps in information are forms of mathematical modeling. Models project the prevalence and incidence of HIV infection and of AIDS in specific regions or populations, assess the possible consequences of interventions aimed at modifying sexual behavior and drug abuse, help plan care for AIDS patients, and extract the most information from existing data on myriad other features of the epidemic. However, existing data are sorely insufficient for definitive projections. Among the greatest needs are better information about seroprevalence in particular risk groups, sexual behavior, the size of the IV drug-abusing population, and the efficiencies of HIV transmission. **The committee strongly supports** continued research efforts to develop better ways to refine predictions about the future course of the AIDS epidemic and to evaluate potential intervention strategies.

The paucity of information on the social science aspects of AIDS has led the National Research Council to establish a committee to study what is known about the behavior that sustains the epidemic. Its first report is due to be released this fall.

ALTERING THE EPIDEMIC'S COURSE

AIDS and the HIV epidemic present a fundamental challenge to the guardians of public health in that certain properties of the HIV epidemic, which distinguish it from other dread diseases, evoke special concerns in fashioning a public health response. One factor is the lifelong infectiousness of virus carriers; another is that private, consensual behavior such as sexual intercourse and IV drug abuse are integral to the disease. A third

factor is that the groups at greatest risk for infection were already vulnerable to social stigma and prejudice.

Public health efforts to combat the spread of HIV should not be limited to programs with "AIDS" in their titles. Appropriate venues for education, testing, and counseling about HIV include sexually transmitted disease clinics, drug abuse treatment centers, physicians' offices, hospitals, and health care clinics. Many of the programs designed to combat venereal diseases and drug abuse have a direct bearing on AIDS. If they lose funds to AIDS programs, the public health could be further imperiled. **The committee believes** that the HIV epidemic should prompt a reexamination of the fiscal and institutional barriers that impede effective public health efforts in all program areas related to the control of HIV infection.

Antidiscrimination Protections

A growing body of evidence bolsters our certainty that persons with HIV infection pose no danger to other persons through casual contact in the workplace, in housing, or in customary social interchanges. Therefore, there is no valid basis for discriminating against persons infected with HIV for fear they pose a health risk to others.

The committee believes that the fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures. Public health programs will be most effective if they are accompanied by clear, strict sanctions to prevent unwarranted discrimination against those who are HIV-infected or at risk for infection.

There is no information with which to determine whether AIDS-related discrimination has paralleled the rise in AIDS cases, but numerous anecdotal accounts portray the difficulties faced by persons with AIDS or even by persons who are members of a risk group. A number of court cases have been filed involving victims of AIDS-related discrimination in a variety of settings (e.g., whether children or teachers with HIV infection should be allowed to remain in school), and complaints have been docketed with state and local human rights commissions. **The committee supports** the enactment of a federal statute specifically designed to prevent discrimination on the basis of HIV infection or AIDS.

Education

Educational efforts to foster and sustain behavioral change are the only means now available to stem the spread of HIV infection. In the past 2 years, programs initiated at the local, state, and federal levels have sought to educate the public in general and high-risk groups in particular.

Nevertheless, formidable obstacles remain to effective AIDS education. The committee believes that the urgency of the HIV epidemic warrants a multiplicity of educational efforts, including the use of paid advertising on television and in other media. A number of federal government entities, including the military, the postal service, Amtrak, and the U.S. mint, currently spend more than $300 million yearly for advertising. Administrative restrictions from the Department of Health and Human Services now preclude CDC from paying for advertising; yet public service advertisements alone are inadequate to the task. **The committee believes** that the gravity of the HIV epidemic is such that CDC, like other government entities, should be allowed to purchase advertising time and space and should be supplied with the funds to do so. Any administrative regulations that preclude such actions should be withdrawn immediately.

The implementation of AIDS education programs has continued to founder over questions involving the content of the programs' message. Information about the modes of HIV transmission must be conveyed in an understandable, yet scientifically accurate form. The message of AIDS education programs must also address sexual behavior and drug abuse. Those matters are regarded by some as immoral and not suitable for description in public health campaigns. Others, however, believe that candid presentations, including explicit language about sex, are necessary to get the message across. **The committee believes** that government at all levels, as well as private sources, should continue to fund effective, factual educational programs designed to foster behavioral change. An amendment to a health appropriations bill passed by Congress last year precluded the use of CDC funds for educational programs whose frank approach could be regarded as promoting homosexual activities. Explicit information on the risks associated with gay sex and the way those risks can be minimized does not "promote or encourage" homosexual activities. Its sole function is to help homosexuals avoid an illness that endangers their lives and those of their sexual partners and costs the nation billions of dollars.

AIDS education programs in schools, once a highly inflammatory issue, are being adopted more widely. By early 1987 half of the nation's largest school districts had begun some kind of HIV education program, but disputes continue about curricula and about who should control their content. **The committee believes** that school-based educational programs are an essential part of efforts to increase awareness of the risk of HIV and to combat the spread of infection. This education should begin at a young age and have a level of detail and explicitness appropriate for the age group. College and university education programs can take into account the possibility that the target audience may be sexually active or abusing drugs.

The public has become more knowledgeable about AIDS over the past few years, but serious misunderstandings persist. A quarter of the general public believes incorrectly that infection can be acquired by donating blood; more than a third incorrectly thinks that mosquitoes can transmit HIV. A fifth believes that they run the risk of becoming infected merely by working near someone with AIDS. **The committee believes** that more studies are needed to determine the effects of various types of educational campaigns on specific populations. For example, there have been few systematic assessments of the effect of AIDS education programs or media presentations on the behavior of heterosexuals (as opposed to the impact on their beliefs or understanding about the disease). Educational efforts aimed at persons at risk within minority communities are also critical: the prevalence of AIDS in the black and Hispanic communities is substantially higher than that among whites, and recent data suggest that the virus is spreading more rapidly among blacks and Hispanics at risk than among other population groups, especially in Northeastern cities.

Homosexual and bisexual men have responded encouragingly to education programs in San Francisco and New York, the U.S. cities hardest hit by the epidemic. That note of reassurance pales, however, beside the estimate that as much as half the male homosexual population in those cities may already be infected with HIV. Some hope lies in the possibility that those who are not infected can still be protected through vigorous educational efforts. **The committee also believes** it is essential to develop effective methods for reaching youth who are just becoming homosexually active.

Condoms are a generally effective means of preventing the spread of many sexually transmitted diseases, including HIV infection. Manufacturers and regulators of condoms have moved to ensure against product failure, but a greater likelihood of disease exposure lies in "user failure." Health care professionals should advise patients in detail about proper condom use and its importance in both heterosexual and homosexual intercourse. One obstacle to more effective AIDS education has been the long-standing refusal of the media to accept commercial condom advertising. **The committee believes** that there must be continued attention to the development of policies to foster the use of condoms.

Screening and Testing for HIV Antibody

Many public health objectives can be achieved through HIV antibody screening (of populations) and testing (of persons), including ensuring the safety of donated blood, tissues, and organs; ascertaining the spread of infection by demographic and geographic surveillance data; diagnosing

patients so they can receive medical care; encouraging individual behavioral change (e.g., refraining from high-risk practices, making reproductive decisions on the basis of test status); facilitating the notification of sexual partners of infected individuals; and improving infection control in hospitals. Yet even as proposals are made to widen the scope of testing, other considerations also come into play. Test results can have psychological and social ramifications; inaccurate results can be devastating; testing and especially counseling are labor intensive and thus expensive; and test results must be protected against disclosure.

The accuracy of currently available HIV antibody tests compares favorably with other medical diagnostic tests. Nevertheless, some false results are inevitable, especially when tests are applied in populations that are at low risk for infection. **The committee believes** the federal government should give more attention to establishing standards for laboratory proficiency in HIV antibody testing, setting criteria for interpreting assays, and instituting quality assurance procedures.

Testing implies that the subject knows the test is being conducted and why, and that the results will be kept confidential so as to avoid all possibility of stigmatization. However, precautions are unlikely to be completely observed unless they are formalized. Thus, **the committee believes** that laws and regulations with strict sanctions to prohibit willful or negligent unauthorized disclosure of HIV antibody test results are an essential component of the public health effort. Confidentiality encourages subjects to volunteer for testing, which is a major tenet of public health programs. Laws and regulations to ensure confidentiality must be matched by conscientious medical recordkeeping to avoid inadvertent disclosure. **The committee believes** that, in addition to reviewing statutory protections of medical confidentiality, it will also be necessary at the local level for hospitals and other medical care institutions to review their recordkeeping policies and apprise their staff of their responsibilities to protect patient privacy.

The belief that a person's knowledge of his or her HIV test results encourages more healthful behavior is a driving force behind much public health policy related to AIDS. The committee believes that tests for HIV infection will play an increasingly useful role in the battle against its spread. **The committee recommends** expanded voluntary testing combined with counseling of all those whose behavior may have put them at risk for exposure to HIV. Those who test positive have a moral obligation to inform and protect their sexual or needle-sharing partners. In addition, **the committee believes** further studies to assess the behavioral impact of testing are essential. Most studies to determine the effects of HIV test results on behavior have enrolled homosexual men in large cities. Virtually nothing is known about such men in rural settings, about teens

only beginning homosexual activity, about women facing family planning decisions, and about other test subjects.

The prospect of mandatory screening raises a number of problems, including the concern that if it is directed toward low-risk groups, it could waste resources that are needed for more effective public health programs. The committee considered the issue of mandatory screening in a variety of contexts and reached the following conclusions.

- **The committee believes** that, at this time, the only mandatory screening appropriate for public health purposes involves blood, tissue, and organ donation.
- Mandatory screening of patients entering the hospital is a questionable practice for purposes of infection control. Instead, **the committee encourages** hospitals and other health care facilities to implement the "universal precautions" recommended by CDC and the American Hospital Association. Nevertheless, for many individuals, being admitted to the hospital is a rare encounter with the health care system. **The committee believes** that, although mandatory screening of all hospital patients is inappropriate, the current situation warrants more widespread use of HIV antibody tests in the hospital setting on a voluntary, informed basis.
- **The committee reaffirms** the position adopted originally in *Confronting AIDS,* that testing marriage license applicants is inadvisable. The committee does, however, support the approach that requires potential applicants for marriage licenses to be informed of the risks of HIV transmission.
- Female prostitutes are frequent targets of proposals for mandatory testing. By engaging in multiple sexual encounters, they tend to contract more venereal diseases than the general public, but the biggest risk factor for prostitutes in the HIV context appears to be IV drug abuse. **The committee believes** that mandatory testing of prostitutes at the time of arrest or as a condition of release is not warranted at this time. **The committee supports** further seroprevalence studies to assess risk in this group and for the larger heterosexual community. Vigorous counseling efforts and the promotion of voluntary testing are necessary to encourage behavioral change among prostitutes.

The committee did not address the related question of mandatory testing of prisoners; however, it believes the issue warrants further study.

Home test kits for HIV antibody have been designed but are not yet on the market for lack of government approval. In addition, serious questions about accuracy, confidentiality, and counseling must be settled prior to their widespread use. However, **the committee believes** that home test kits and their associated questions warrant careful review. There may

well be persons who are wary of encounters with the health care system or who fear being seen at a test site. For these people, home-based testing may become an appropriate alternative.

Other Public Health Measures

The law has traditionally recognized an exception to the requirement for confidentiality in situations in which third parties may be at risk. Case law on the books in many states spells out the duties of physicians to warn specific individuals of foreseeable dangers, including the risk of infection. Arguments against applying the duty to warn to persons with AIDS or to asymptomatic seropositive individuals hold that the failure to respect professional confidentiality obligations would deter patients from seeking care and would drive the disease underground. The American Medical Association has put forth guidelines about a physician's duty to warn third parties who may be at risk for infection, but questions of legal liability remain. Provisions of the AIDS Federal Policy Bill of 1987 allow physicians to use their discretion in warning third parties. Although the bill does not impose a duty on physicians one way or another, it does protect them from liability in the event of breached confidentiality in such circumstances.

Contact notification is a classic measure in venereal disease programs, but even in states in which laws demand that health officials ask for the identities of the sexual partners of an infected person (i.e., the "index case"), infected individuals are not compelled to disclose that information. The use of contact notification has been defended in venereal disease programs on the grounds that finding contacts in cases of syphilis or gonorrhea can lead to successful treatment—which is not yet true in HIV infection. Confidentiality is a major concern, although the record of public health officials in maintaining the confidentiality of information is remarkably good. On balance, **the committee believes** that voluntary contact notification programs can be useful in preventing the spread of HIV infection.

Reporting by health officers of seropositive persons is required in a dozen states. Although some arguments for mandatory reporting have merit, the committee has concluded that the costs far outweigh the benefits, especially if mandatory reporting discourages individuals from seeking voluntary testing. **The committee believes** that mandatory reporting of seropositive test results with identifiers should not be required at this time.

Isolating or otherwise restricting the freedom of infected carriers who refuse to protect others from infection historically has been a common means to prevent the spread of infection in other diseases. **The committee**

believes that there may be rare instances in which the state should act to restrict the personal liberties of some infected individuals, and states should review their statutes to ensure that such authority exists. Legal measures to restrict personal liberty should be used only when the following conditions have been met: (1) the person is infected, (2) the person is putting others at risk, (3) voluntary efforts to prevent such exposure have failed, and (4) the restrictive measure used is the least forceful appropriate to the task. Furthermore, restrictive measures should also entail the provision of intensive counseling, job training, and other supportive actions to induce behavioral change. The period involved should be short and clearly limited.

AIDS and IV Drug Abuse

Since the publication of *Confronting AIDS,* there has been widening recognition of the peril that HIV poses for the IV drug abuser, his or her sexual or needle-sharing partners, and their offspring. IV drug abusers are the second largest group of AIDS sufferers, and they are the most likely to transmit HIV to heterosexual partners. **The committee believes** that the gross inadequacy of federal efforts to reduce HIV transmission among IV drug abusers, when considered in relation to the scope and implications of such transmission, is now the most serious deficiency in current efforts to control HIV infection in the United States. The waiting lists for entry into treatment programs are a clear indication that the caliber of the ammunition in the war on drugs needs to be increased. **The committee urges** a greater commitment on the part of federal, state, and local governments to the rapid, large-scale expansion of drug abuse treatment slots, both in residential drug-free treatment centers and in methadone maintenance facilities, to offer immediate access to all addicts who request treatment.

Currently, no more than 20 percent of IV drug abusers attend treatment programs in any given year. To reach those who are not in treatment, innovative intervention programs are appearing in some localities. **The committee supports** the increased use of former IV drug abusers as community health workers to provide "one-on-one" risk reduction counseling and materials to drug abusers who are not in treatment, including instruction in the use of bleach to sterilize injection equipment. Our predecessor committee called for experimental programs to distribute sterile needles and syringes. **The present committee continues to believe** that evaluation of the effectiveness of providing sterile needles and injection equipment to drug abusers in certain circumstances is an essential part of planning a prevention strategy. In addition, **the committee supports** the immediate extension of serologic testing and counseling for HIV infection to all appropriate settings in which IV drug abusers are

seen. Programs should also be developed to promote self-help support groups of former and current drug abusers as a means of education about AIDS and drug abuse in at-risk groups. Among long-term strategies that deserve more attention, the committee favors greater efforts to educate teens and preteens in high-risk populations about the dangers of drug abuse. Research and evaluation are necessary to determine which interventions work best.

Resources for Public Health Measures

The variety of funding sources for public health campaigns against HIV makes it difficult to determine if substantial progress is being made toward one of the goals in *Confronting AIDS:* providing by 1990 "newly available funds" totaling $1 billion a year for public health and education. Federal, state, and local governments, together with private sector sources, have made heartening contributions to the effort. Nevertheless, it is becoming apparent that present funding is insufficient for public health approaches to stem the epidemic. Perhaps the single greatest concern is the lack of availability of treatment facilities for IV drug abusers and the lack of support for programs to eliminate or reduce drug abuse or to mitigate the danger of shared injection equipment. **The committee believes** that a substantial sum of money will have to be spent for these purposes, well beyond the $1 billion originally proposed for AIDS public health and education measures. In addition, funds are needed to support expanded counseling programs linked to HIV-antibody testing and increased educational and outreach efforts among minority groups.

CARE OF PERSONS INFECTED WITH HIV

The relatively sudden appearance of large numbers of patients with a disease notable for its medical complexities and thorny social and ethical issues has highlighted inadequacies in current medical practice and the health care system. In the past 2 years, some progress has been made in improving care for patients with HIV infection and AIDS, but many of the recommendations in *Confronting AIDS* have not been addressed.

Care Needs of Special Patients

Almost by definition, AIDS patients are special patients. Their optimal care would be delivered by a multidisciplinary team of providers in facilities specializing in AIDS treatment, with effective discharge planning services to ensure the continuity of care. However, particular subgroups of AIDS patients deserve special consideration.

IV drug abusers without HIV infection pose substantial problems for the health care system because they are likely to be poor, in generally bad health, and homeless. Adding AIDS to these difficulties makes the provision of care more complicated. Even when community agencies have the resources to provide care for IV drug abusers with AIDS, they may not be eager to extend services to them or to their families. **The committee believes** that more long-term residential facilities or group homes are needed for AIDS patients who are IV drug abusers. Those patients with ongoing substance abuse or mental illness, or both, in addition to AIDS, have a special need for these facilities.

Infants and children with AIDS are a growing problem. Most of them have been infected by their mothers either before or at birth, and the mothers often are too sick to care for their children. Pediatric AIDS further disrupts families that may be already weakened as a result of parental drug abuse or HIV infection. Consequently, with few resources and social supports, pediatric AIDS patients remain hospitalized for prolonged periods. **The committee urges** that foster care, community-based residential care, and hospice care programs be developed or expanded to meet the needs of pediatric AIDS patients and their families so that hospitals are no longer the "home of last resort."

Patients with dementia or other neurologic disorders often require custodial care more than treatment, and extended care facilities are generally the setting of choice. However, such institutions do not exist in many areas, and when they do, their proprietors may be reluctant to take AIDS cases. **The committee recommends** that skilled nursing facilities or nursing homes providing inpatient long-term or hospice care be made available to AIDS patients who require these services—for example, through the construction of AIDS-dedicated facilities or by offering incentive payments to facilities that are willing to accept AIDS patients.

Health Care Providers

Although health care professionals continue to enter the field of AIDS patient care, they are not being recruited at a rate commensurate with the epidemic's growth. For one thing, providers have had to reexamine some of the tenets of their professions concerning the care of patients who may expose them to some risk of infection. Although the probability that a health care worker will acquire HIV infection on the job is low, it is not zero. Agencies such as CDC and the Department of Health and Human Services, together with the Occupational Safety and Health Administration (Department of Labor), have established guidelines for infection control that encourage greater vigilance in the handling of every patient, whether or not HIV infection is known or surmised.

Emergency care personnel and surgeons, who presumably are more likely to be exposed to HIV, are among those health care providers expressing heightened concern about infection and questioning their ethical obligation to treat HIV-infected patients. Reactions such as these have led professional groups (e.g., the American Medical Association and the American Nurses' Association) to issue policy statements against prejudicial approaches to ethics and duty. **The committee believes** that the health professions have a compact with society to treat patients with all forms of illness, including HIV infection and AIDS. To deny or compromise treatment to any patient on the grounds that a medical risk is posed to the provider breaks the fundamental trust between patient and caregiver. However, health care personnel also deserve to know the occupational risks they face in caring for infected patients. **The committee recommends** that assessments of the risk of occupational transmission of HIV continue and that new data be disseminated as widely as possible. Techniques to further reduce the risk of occupational HIV transmission should also be explored.

There have been no reported cases of the infection of a patient by a seropositive caregiver in the course of treatment. Nonetheless, a theoretical risk of such infection exists, and it has raised the issue of whether or not health care personnel should be screened for HIV antibodies. **The committee recommends** that the Institute of Medicine convene a conference on the ramifications of routine testing for HIV antibodies in health care workers.

The care of AIDS patients is sufficiently complex as to require personnel of many different skills, all trained in the context of the HIV-caused disease. Such training is being expanded, but the personnel supply lags far behind the demand. **The committee believes** that it is the responsibility of the health professions to stimulate adequate training in HIV infection and AIDS. One way to speed this process is to incorporate questions about AIDS and HIV infection into examinations for medical speciality and subspeciality board certification and state professional licensure; another is to offer continuing medical education courses. **The committee recommends** that basic curricula in education programs of all medical and health professions be modified to ensure adequate training in the diagnosis, prevention, and treatment of HIV infection and AIDS, as well as in infection control measures.

Doctors and nurses alike have begun to report increasing psychological and emotional strain from working with AIDS patients. Fears of becoming infected, the higher level of care needed for patients who often suffer severe physical and mental deterioration, and the "emotional brutalization" that comes from providing such care are common. There are few formal support groups for these beleaguered providers, although they must maintain their own health in order to give effective care. **The**

committee recommends that research funding be made available to examine the feasibility and study the effectiveness of programs to alleviate stress in health workers who care for AIDS patients.

Costs of Health Care for Persons with AIDS

Concern has been steadily growing over the economic impact of HIV infection and AIDS on the nation's health care system. However, data to assess the current situation and project the future economic burden are scarce. The direct costs associated with AIDS include hospital and physician services and nursing home and hospice care, as well as biomedical research and public health campaigns. The average lifetime medical expenses (from diagnosis to death) per AIDS patient are estimated to be between $65,000 and $80,000. Indirect costs of the disease include the loss of wages because of illness and the loss of future earnings (which is great because AIDS kills young adults in their most productive years). Most recently, indirect costs have been estimated at $7 billion for the prevalent cases in 1986. Projections of the spread of the disease by 1991 give rise to estimated expenditures totaling $66.5 billion for that year, of which $55.6 billion would be indirect costs.

Health services research, which was strongly recommended in *Confronting AIDS,* has been expanded in the past 2 years and should soon begin to identify the total direct costs of AIDS care, make comparisons of AIDS treatment costs with those of other diseases, compare costs among various stages of HIV-related illness and AIDS, and rank the cost-effectiveness of various organizations of service.

Financing Health Care for Persons with AIDS and Other HIV-Infected Individuals

The problems of financing care for persons with AIDS and other HIV-related conditions reflect the inequities in the entire U.S. health care system in relation to the uninsured and uninsurable, the plight of the poor in getting care, continuing underfunding for disease prevention, insufficient capabilities for care outside of institutions, and inadequate care for the chronically ill. **The committee believes** that all individuals have a right to equitable access to adequate medical care and that society has an ethical obligation to ensure such access.

In the meantime, Medicaid covers health care for much of the welfare population, including 40 percent or more of AIDS patients. Medicare, for the aged and disabled, covers very few AIDS patients because they often do not survive the required waiting period to qualify for benefits. Private health insurance may be covering a dwindling share of AIDS patients

because of changes in patient demographics and because insurers are making plans to limit their exposure to financial risk.

Possible Financing Mechanisms

The committee has examined a number of proposals to improve health care coverage for persons with AIDS and other HIV-infected individuals. Some would encourage private insurers through government subsidy; others would modify Medicaid to make it more uniform among the states; still others would set up state insurance risk pools. The committee appreciates the concerns that have been voiced about singling out AIDS patients and others with HIV-related illnesses for special consideration in the financing of health care. However, because the AIDS crisis is disrupting the health care delivery system in many areas of the country, an interim financing solution is needed. **The committee endorses** an AIDS federal grant program as an interim measure to ensure that AIDS patients and those with HIV-related conditions have access to appropriate and cost-effective care.

A federal task force has recommended that state Medicaid and private insurers consider reimbursement, but with cost-sharing provisions to limit the burden on public funds, for costly AIDS therapies once the Food and Drug Administration has approved them for treatment under a special new status called the treatment investigational new drug, or IND. **The committee would extend** the task force recommendation to require such reimbursement. However, in the future, it may be necessary to develop a mechanism to establish priorities for coverage among potential therapies.

Although an AIDS federal grant program directing money to the states and reimbursement for costly experimental therapies would be temporary solutions to the problems of health care financing, a more comprehensive and equitable scheme is needed. **The committee urges** the federal government to take the lead in developing a comprehensive and coherent national plan for delivering and financing care for HIV-infected and AIDS patients. Any financing strategy of this kind should be guided by the following principles: (1) coverage from the time of HIV infection, (2) consideration of relief for hard-hit communities, (3) shared responsibility between public and private sectors for the financing of care, and (4) payment mechanisms that encourage the most cost-effective types of care.

THE BIOLOGY OF HIV AND BIOMEDICAL RESEARCH NEEDS

HIV Biology

Appreciable progress has been made recently in understanding how HIV compromises human defenses and causes AIDS. As our knowledge

increases, however, so does its complexity. A second human retrovirus, HIV-2, has been identified and linked to a growing number of cases of immunodeficiency diseases that are clinically indistinguishable from the disease caused by HIV-1. HIV-2 infection is most prevalent in West Africa. Researchers have also discovered that the HIV-1 genome contains a number of novel genes that are without known counterparts in other retroviruses. Further understanding of the functions of these genes and the proteins they code for could speed the development of drugs and vaccines against AIDS. In the meantime, more viruses that strongly resemble HIV are being found in monkeys, cows, and cats, a development that may lead to valuable animal models of AIDS.

The HIV replicative cycle offers a number of opportunities for interruption by antiviral interventions. The recent discovery that the HIV-1 target cells have a particular molecule (called a CD4 receptor) on their surface that binds to an envelope protein of HIV-1 (gp120) has made this stage of HIV replication the object of increased attention. Another area of consideration involves the inhibition of reverse transcriptase, the lack of which would disrupt another essential replicative stage. Researchers also now recognize that the cells that are targets for HIV include the macrophages as well as the particular T cells of the immune response. The macrophages not only migrate freely but, unlike the T cells, are not greatly harmed by virus infection. Macrophage transport of HIV into the brain may be the cause of AIDS dementia.

Studies of HIV have revealed a variety of processes that were not previously known to occur in human cells, another example of the classic dependence of science on serendipity for unanticipated answers. For this reason, increasing the funds devoted to AIDS without a concomitant strengthening of all basic biomedical research is shortsighted. Thus, **the committee recommends** that funding for basic research in all areas of biology should continue to grow rather than be curtailed in favor of AIDS-targeted research.

Drug Development and Testing

Applying recent accomplishments of basic research to drug development requires organizational coordination. A promising new form of such cooperation is the National Cooperative Drug Discovery Groups of the National Institute of Allergy and Infectious Diseases (NIAID). Groups such as these and other investigators are exploring new approaches to drug development, as well as screening existing compounds for possible effectiveness against HIV. One example of a new treatment approach that is currently being tested is the combination of zidovudine (i.e., AZT) with an immune response modifier such as macrophage colony-stimulating factor.

The U.S. drug approval process, which is regulated by the Food and Drug Administration (FDA), is the most rigorous in the world. The approval of a new drug generally involves tests in animals and then a three- or sometimes four-phase series of clinical (human) trials for safety and efficacy. However, in response to the urgency of the AIDS crisis, FDA has moved to speed up some portions of its review and has established a new category of investigational new drugs called the treatment IND, which allows manufacturers to distribute a drug for use before FDA review has been completed.

A prototype of this procedure brought zidovudine (AZT) into relatively wide use quickly; more recently, trimetrexate, a drug used to treat the pneumonia common to AIDS patients, was approved under the new regulations. Yet FDA action for greater alacrity in getting drugs into testing, coupled with the intensity of drug development surrounding AIDS, could tax the agency's present capabilities. **The committee believes** that FDA resources for new drug approval should be commensurate with the task. In addition, although the ingenuity of FDA in designing new regulations to hasten the availability of drugs against HIV is admirable, **the committee recommends** that an outside evaluation of the treatment IND process be conducted after enough time has elapsed to determine its possible unanticipated consequences for any new drugs.

HIV infection and AIDS have generated a pressing need to develop and test experimental drugs and to make effective drugs widely available as soon as possible. The committee recognizes the frustration, fear, and anger of people with HIV infection, who may feel a lack of urgency in the drug development process. Nonetheless, **the committee believes** that once drugs are through phase I testing for toxicity, carefully controlled trials are still the fastest, most efficient way to determine what treatments work.

Although the best-designed clinical trial would enroll the fewest people needed to demonstrate a drug's effectiveness, persons with HIV infection want very much to participate in clinical trials. **The committee believes** that, following scientifically sound guidelines, wider access to clinical trials can be gained by broadening their geographic base, by extending trials to previously untapped populations including women, IV drug abusers, and pediatric patients, and by testing all compounds that might possibly be effective. Those groups conducting trials have the responsibility to communicate with the public about their availability and to encourage wide participation.

NIAID's establishment of AIDS clinical trial units (ACTUs) across the nation offers a mechanism for such communication. The 35 ACTUs are sites at which investigators and patients can be enlisted for large-scale, standardized collaborative clinical trials to determine the worth of a new drug. **The committee believes** that, to the greatest extent possible, trials should take place within well-established sites for drug testing.

Finally, the committee abhors the exploitation of people with HIV infection and AIDS by those promoting and selling "effective" therapies that are in fact unproven.

Vaccine Development and Testing

The prevention of HIV infection by vaccination continues to pose fundamental difficulties. Most of the experimental work employs portions of the viral envelope as the vaccine antigen to eliminate the possibility that the vaccine itself could be infectious. Vaccines of this type have been shown to induce antibody synthesis in mice and chimpanzees, including synthesis of neutralizing antibodies, which block HIV infection in tissue culture. However, the neutralizing antibodies did not block HIV infection in chimpanzees. These experimental results tend to mirror clinical observations, in which no correlation is seen between the level of neutralizing antibodies and the progress of the natural infection in patients.

We are no closer now to having a licensed vaccine against HIV than we were 2 years ago. Nevertheless, experiments point to some procedural measures that should be taken when a potential vaccine is found. The vaccine approval process is similar to that for drugs in that candidate vaccines are tested in three phases of trials, the last being a large-scale, controlled field trial with a sufficiently large number of subjects (at sufficiently high risk of infection) to determine whether the vaccine protects people (at a statistically significant level) against disease. FDA standard practice has generally been that a vaccine must show protective efficacy in an accepted animal model before tests can progress to human volunteers. However, given the potentially disastrous effects of the AIDS epidemic, FDA has approved human trials for two vaccine candidates in the absence of proof of protective efficacy in animals. There has been appreciable controversy about the wisdom of this move. **The committee believes** that human trials of HIV vaccine candidates should proceed only when (1) protection against infection has been demonstrated in chimpanzees (HIV), in macaques (SIV), or in another suitable animal model or (2) the vaccine candidate rests on fundamental new knowledge of the relevant human response that cannot be adequately modeled in animals. **The committee also believes** that planning should begin now for large-scale human efficacy trials of as yet undeveloped vaccines.

Roundtable on Drugs and Vaccines

The Institute of Medicine (IOM) conducted conferences in 1987 on the development of drugs to treat AIDS and the development of vaccines to prevent HIV infection. Each of the two events brought together scien-

tists, clinicians, pharmaceutical industry representatives, and policymakers to consider ways to speed the availability of effective therapy and protection against HIV. The participants found the meetings so productive that they asked the IOM to undertake additional conferences. As a result, IOM has established the Roundtable on the Development of Drugs and Vaccines Against AIDS to spur progress in the discovery, regulation, legislation, and clinical application of measures to stem the epidemic. **The committee endorses** the establishment of the Roundtable on the Development of Drugs and Vaccines Against AIDS and encourages active participation by all sectors.

Animal Models of AIDS

The development of model systems, in which an animal infected with HIV shows the same symptoms and exhibits the same course of disease progression found in human AIDS patients, is essential to the campaign against the disease. The use of simian immunodeficiency virus (SIV) to infect Old World primates such as rhesus macaques results in an animal model that quickly develops an AIDS-like disease with a subsequent high death rate. **The committee believes** that SIV infection in macaques and the resulting disease are the best parallels at this time to human HIV infection and should be vigorously exploited. However, chimpanzees will also continue to figure prominently in AIDS research; for example, they are now the animal of choice when HIV is used to challenge vaccinated animals to determine whether a vaccine provides safe, effective protection. Yet chimpanzees for research purposes (like other primates) are in short supply. Thus, **the committee recommends** that plans for breeding, conserving, and otherwise expanding the present stock of chimpanzees be examined. This expansion may require increased funding.

Considering the amount of experimental work that lies ahead to stem the epidemic, the exclusive use of primates as animal models is infeasible. A small animal model is also desirable; in particular, a mouse model (mice being small, plentiful, and well understood) would be a veritable breakthrough in AIDS research. **The committee believes** that whatever its final form, the development of a small animal model for AIDS is of utmost importance. If efforts to develop such a model are carried out under carefully regulated, safe laboratory conditions, the committee would strongly support further work in this area.

Resources for the Campaign

Existing facilities are inadequate for further advances in research against HIV: very few laboratories are equipped to handle the virus

safely. The federal government has provided additional funding of $24 million for the National Institutes of Health (NIH) to channel to extramural sites for facility improvement, and more than $19 million has been appropriated for NIH intramural upgrading. These new allocations, however, are only a modest beginning in the facility improvements needed for AIDS research. **The committee recommends** that the director of NIH, in consultation with research scientists from within and without the institutes, assess the need for and costs of new intramural and extramural facilities for AIDS research. This information should be forwarded to Congress for evaluation and subsequent action.

To support AIDS research by providing reagents to scientists, NIAID has established the AIDS Research and Reference Reagent Program. Scientist participation at this point, however, is only voluntary. **The committee recommends** that NIH stipulate that all investigators receiving NIH funds must make their AIDS-related reagents available to the distribution center, and thereby to all qualified investigators, after publication of their research. In addition, **the committee supports** the development by NIH, perhaps through the reagent program, of an HIV/SIV research "starter kit" that would enable qualified new investigators to begin research more easily.

Confronting AIDS recommended that federal appropriations for research related to this disease reach at least $1 billion a year by 1990. At the present rate of increase, it appears that this goal will be met. The 1988 NIH budget for AIDS research is $467.8 million, and the proposed 1989 budget is $587.6 million. Approximately $300 million more is proposed for AIDS research in 1989 by the Centers for Disease Control, the Alcohol, Drug Abuse, and Mental Health Administration, and FDA. **The committee believes** that when federal research expenditures for AIDS reach $1 billion annually, an assessment of the need for further increases should be made. It is important to ensure that other federal research programs are not penalized by a long-term disproportionate growth of the AIDS budget.

INTERNATIONAL ASPECTS OF AIDS AND HIV INFECTION

Of the 158 countries or territories that report to the World Health Organization (WHO), 133 had at least one case of AIDS as of March 1988. A cumulative total of more than 81,000 cases has been reported from countries on all continents. However, the reporting of cases to WHO is incomplete. U.S. officials estimate that the U.S. reporting system captures only about 80 percent of AIDS cases; much smaller proportions of actual cases are probably being captured in countries with few or any epidemiological data systems. Consequently, WHO estimates that there

are at least 150,000 AIDS cases worldwide and between 5 and 10 million (closer to 5 million) HIV-infected persons.

Three patterns of AIDS are differentiated on the world map. In North America, parts of South America, many Western European countries, Australia, and New Zealand, most AIDS cases occur among homosexual or bisexual men and urban IV drug abusers. In most of Africa and parts of the Caribbean, most cases occur among heterosexuals. In Eastern Europe, the eastern Mediterranean, Asia, and most of the Pacific, only small numbers of cases have been reported thus far. The WHO Global Programme on AIDS has been working in the past year to (1) provide support to national AIDS control and prevention programs and (2) conduct global AIDS-related activities (e.g., surveillance and research in the biomedical, social, and epidemiological sciences).

The rationale for United States involvement in international AIDS activities is more broadly based than the protection of American troops and tourists. AIDS can destabilize the work force and the economy in developing countries whose advancement has been aided by U.S. dollars. AIDS can also reverse the advances in infant and child survival in countries in which our help only recently has brought improvement. Finally, some countries offer promising opportunities for collaborative AIDS research because they have different disease patterns and a higher prevalence of HIV-2 infection.

American activities in international work against AIDS are conducted by many federal agencies. Contributions to WHO's Global Programme were $1 million in 1986 and $5 million in 1987; they will be about $15 million in 1988. Philanthropic foundations are also beginning to fund AIDS activities. In addition to these contributions, however, **the committee believes** that the United States has a special responsibility in international health efforts to control AIDS because of our exceptional resources in public health specialists and biomedical scientists, the large number of infected persons in the United States, and our relative affluence.

WHO's program on AIDS is also supported, in a sense, by the other divisions of WHO, which are funded by regular budget assessments of assenting United Nations member countries. At last reckoning, the United States was in arrears on its regular budget assessment. **The committee strongly urges** that the United States pay its assessed contributions to WHO in total as soon as possible.

The committee is encouraged by the United States' response to the needs of the international campaign against AIDS. Yet effective planning for U.S. participation requires that we know the detail and extent of activities in which we are already engaged. The committee responsible for *Confronting AIDS* could find no such information 2 years ago; the present committee has also failed to find these data. **The committee urges** that a

data base for international AIDS research activities be established and maintained.

A NATIONAL COMMISSION ON HIV INFECTION AND AIDS

In *Confronting AIDS*, the Institute of Medicine/National Academy of Sciences (IOM/NAS) Committee on a National Strategy for AIDS highlighted deficiencies in the efforts being directed against the AIDS epidemic and in the employment of the nation's resources in that task. The 1986 report also identified as a major concern a lack of cohesiveness and strategic planning throughout the national endeavor and recommended the creation of a national commission on AIDS.

The committee carefully weighed the question of whether or not to reaffirm the IOM/NAS recommendation to establish a national commission on AIDS, and in doing so evaluated the quality of leadership in several components of government and in the private sector. The Presidential Commission on the Human Immunodeficiency Virus Epidemic (which concludes the work authorized by its year-long charter in June 1988) has demonstrated the effectiveness of focused attention in bringing diverse public and private resources to bear on a national problem. Unfortunately, however, the commission is short-lived. The coordination offered by the Federal Coordinating Committee on Information, Education, and Risk Reduction on AIDS, chaired by the assistant secretary for health of the Department of Health and Human Services (HHS), has facilitated communication but has not set policy that spans all departments of the executive branch. Within HHS, coordination has been carried out by the Public Health Service Executive Task Force on AIDS. Two new offices, the National AIDS Program Office (to expand and replace the task force) and, at the NIH level, the Office of AIDS Research, will continue to streamline progress within the Public Health Service, but their responsibility is not the overarching leadership that the committee feels is lacking. Finally, private organizations, state and local governments, foundations, volunteer groups, and professional organizations have all made enormous contributions, but the absence of a coherent national policy condemns many of them to "reinvent the wheel" when it comes to AIDS policies and programs.

Still, there have been areas of progress: biomedical research, some improvements in public education manifested in the recent all-household mailing planned by CDC and the continuing superb leadership of Surgeon General C. Everett Koop, improvements in the FDA drug approval process, and the ongoing CDC surveillance efforts. Nevertheless, the committee has concluded that the federal response has been too uneven. Inadequacies persist in the provision and financing of health care, in

setting standards for antibody testing and antidiscrimination, in addressing IV substance abuse, and in furnishing overarching direction for all components of the government and the private sector. The committee considered a separate AIDS agency to remedy these deficiencies but concluded that such a body, cutting as it would across already established programs, would cause unnecessary disruptions.

The nation has suffered from the absence of strong federal leadership. Although generally reluctant to recommend the establishment of new government entities, in light of past successes with the commission approach (e.g., the Social Security Commission), the committee reaffirms the 1986 recommendation that a national commission on AIDS and HIV infection be established. The committee would assume an advisory rather than an operating role and be responsible for:

- adopting as its scope a broad view of the epidemic that spans all components of the public and private sectors;
- monitoring the course of the epidemic;
- evaluating research, health care, and public health needs;
- formulating recommendations for altering the direction or intensity of health care, public health, and research efforts as the problem evolves;
- setting the tone for educational campaigns;
- assuming an advisory and catalytic role in stimulating appropriate action by federal, state, and local government bodies, industry, the academic scientific community, and private foundations and organizations;
- encouraging greater U.S. contributions to international efforts;
- monitoring and advising on related legal and ethical issues;
- reporting to the American public to clarify points of possible confusion such as the extent and danger of heterosexual spread or the effectiveness of condoms; and
- providing a forum for all involved and interested parties.

To carry out these responsibilities, the commission must have certain attributes. It should:

- be endorsed at the highest levels of government—both by the President and Congress;
- have sufficient national and international stature and credibility for its advice to influence all participants in the struggle against AIDS; and
- be able to engage all of the diverse public and private resources that can be brought to bear on AIDS and its associated problems.

Considering these responsibilities and attributes, the committee proposes the establishment of a national commission on AIDS with a 5-year, renewable term. The commission chair should be a senior, recognized

leader, engaged full time in this capacity and reporting directly to the President. In addition to the chair, the commission should consist of eight other members, each of whom is a senior expert of national stature in one of the areas of particular relevance to AIDS. Each commissioner should in turn head a panel of experts to explore such topics as research (biomedical, health care services, and social sciences), the provision and financing of health care, public health and education, epidemiology and modeling, law and ethics, and the United States' international role in combating AIDS. The commission should have ample professional staff and a sufficient budget. In addition, consideration should be given to establishing a $10 million discretionary fund that would be spent through existing agencies to allow quick responses to new, unforeseen opportunities.

The establishment of a national commission signals a major commitment to national leadership for preventing and controlling HIV infection and AIDS. HIV infection is a rapidly moving target; a sustained, well-guided effort is needed if we are to remain attentive to its course and thwart its effects.

NOTE: Reference documentation for material in this Executive Summary is presented in the respective chapters of the full report.