

GAO

Briefing Report to the Chairman,
Subcommittee on Labor, Health and
Human Services, Education and Related
Agencies, Committee on Appropriations,
United States Senate

August 1987

AIDS PREVENTION

Views on the Administration's Budget Proposals



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Human Resources Division

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August 12, 1987

The Honorable Lawton Chiles
Chairman, Subcommittee on Labor,
Health and Human Services,
Education and Related Agencies
Committee on Appropriations
United States Senate

Dear Mr. Chairman:

This briefing report responds to your June 16, 1987, request concerning the level of fiscal year 1988 funding needed to limit the further spread of acquired immunodeficiency syndrome (AIDS). You asked that we explore both the adequacy of the funding levels proposed for the Department of Health and Human Services' Public Health Service and the appropriateness of priorities reflected in the administration's proposed budget for AIDS prevention. As agreed with your office, we focused on education, testing, and counseling services.

BACKGROUND

In 1981, the federal budget included \$200,000 for the Centers for Disease Control to study AIDS. For fiscal year 1988, the proposed federal Public Health Service budget had increased to more than \$790 million for AIDS research and prevention programs. Of this budget, about two-thirds (\$519 million) would be spent on biomedical research to find a vaccine and cure, while one-third (\$247 million) is intended for prevention and education activities. (The proposed budget also includes \$24 million for maintaining the safety of the blood supply and other activities.)

Since a vaccine is at least 5 years into the future and probably longer, federal, state, and local health department officials and experts in the research community agree that education and prevention activities are the most powerful tools available to reduce the potential impact of the AIDS epidemic. Investing in prevention now can help contain the future direct medical costs of treating AIDS--estimated to reach \$8.5 billion in 1991 (or 1.4 percent of total personal health expenditures, up from 0.2 percent in 1985). In addition, the indirect costs of losses in productivity associated with premature death may reach over \$55 billion

by 1991. This estimate does not include the costs of AIDS-related complex, a broad spectrum of diseases caused by infection with the AIDS virus. Moreover, these costs are based on a Public Health Service estimate that 20 to 30 percent of people infected with the virus would develop AIDS. Since then, however, some scientists have concluded on the basis of more recent epidemiological data that 50 percent or more may develop the disease.

The highest cumulative numbers of AIDS cases are in New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, Massachusetts, Georgia, and the District of Columbia. By 1991, however, 80 percent of all cases are expected to be reported from areas outside of New York and San Francisco--the two cities currently bearing the brunt of the epidemic.

METHODOLOGY

To assess the justification for the adequacy of the administration's AIDS prevention budget, we (1) determined priority areas for preventive action by interviewing experts and reviewing the literature, (2) compared the administration's prevention budget priorities with those we identified, (3) obtained proposed funding levels for these prevention activities from Public Health Service budget officials, and (4) interviewed experts with both nationwide and state and local perspectives to determine their relative priorities and their views on the adequacy of available resources to reduce the spread of AIDS. We also asked state and local health department officials how they would allocate additional resources among their prevention programs. We interviewed experts from the research and health professional communities, advocacy groups, and local health departments in New York City, San Francisco, Los Angeles, Miami, Washington, D.C., Chicago, and Boston (see app. I). The views reported are not necessarily those of the organizations with which they are affiliated.

RESULTS IN BRIEF

Overall, the experts we interviewed generally concurred with the priorities reflected in the administration's AIDS prevention budget for fiscal year 1988. Those areas targeted for immediate action are

-- containing the spread of the AIDS virus among intravenous drug users as well as from this risk group to their sexual partners,

- educating targeted high-risk groups and the general population, and
- expanding voluntary testing with pretest and posttest counseling services.

The administration's budget request includes \$155 million for education and \$92 million for counseling and testing services. These amounts include \$70 million targeted at intravenous drug users (\$55 million for education and \$15 million for counseling and testing). There was consensus among the experts that these proposed funding levels for prevention activities were not adequate. Specific budget increases suggested by one or more of the experts, which they developed without regard to competing federal health priorities or fiscal constraints, were

- \$65 to \$215 million for massive educational campaigns targeted at high-risk groups and minorities as well as at the general population;
- \$50 to \$150 million for drug treatment, primarily aimed at methadone maintenance to reduce heroin injection; and
- \$250 million for expanded capacity at voluntary testing and counseling centers.

Although we did not develop our own funding recommendations, we offer comments that may minimize the need for federal cost increases suggested by the experts.

In addition, they recommended a full-scale federally coordinated campaign against AIDS. Many told us that the perceived lack of federal leadership is at least as troublesome as estimated shortfalls in the budget.

The experts also suggested that the budget should explicitly earmark funds for evaluation of educational efforts to ensure that future dollars can be funneled to the most effective prevention programs. Moreover, since time is of the essence in curtailing this epidemic, they encouraged launching several approaches simultaneously, with evaluation a mandatory component of each project.

State and local health department officials also stressed that their staffs are frustrated by the piecemeal nature of federal, state, and local funding and the administrative requirements for obtaining such funds. This takes staff away

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from working on preventing the spread of AIDS and delivering services to patients.

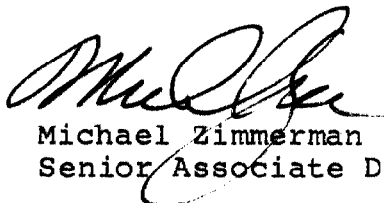
Finally, officials in areas hit hardest by AIDS and the experts we interviewed concurred that more education must be directed at population groups with low rates of infection, particularly heterosexuals, so they may remain uninfected. They believe it is more cost-effective to fund educational programs in areas currently experiencing low infection rates than to wait and be faced with the costs involved in treating, testing, and counseling after infection rates increase. Keeping rates of infection low in these areas also creates the greatest potential for containing the epidemic and reducing the projected number of cases for the 1990's. Future caseloads in high-incidence areas can also be decreased by reducing transmission of the AIDS virus, although those who are already infected may progress from infection to disease whether or not preventive efforts are made.

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As requested by your office, we did not obtain agency comments on this briefing report. The views of agency officials, however, have been incorporated where appropriate. Unless you publicly announce its contents earlier, we plan no further distribution until 30 days from the report's issue date. At that time, we will send copies to other congressional committees having jurisdiction over the matters discussed in the report, the Secretary of Health and Human Services, and other interested parties.

If you have any questions, please call me on (202) 275-6195.

Sincerely yours,


Michael Zimmerman
Senior Associate Director

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Abbreviations

| | |
|--------|---|
| ADAMHA | Alcohol, Drug Abuse, and Mental Health Administration |
| AIDS | acquired immunodeficiency syndrome |
| AMA | American Medical Association |
| AZT | Azidothymidine |
| CDC | Centers for Disease Control |
| FDA | Food and Drug Administration |
| HHS | Department of Health and Human Services |
| HIV | human immunodeficiency virus |
| HRSA | Health Resources and Services Administration |
| IOM | Institute of Medicine |
| IV | intravenous |
| NIH | National Institutes of Health |
| OASH | Office of the Assistant Secretary for Health |
| PHS | Public Health Service |

**AIDS: VIEWS ON THE
ADMINISTRATION'S BUDGET PROPOSALS**

INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is a fatal disease that severely compromises the human body's ability to fight infections. In October 1986, the U.S. Surgeon General reported that AIDS is spread not by casual contact, but primarily through intimate sexual contact and the sharing of hypodermic needles by intravenous (IV) drug users. In addition, infected mothers can transmit the disease to their offspring. AIDS can also be spread via contaminated blood to persons receiving transfusions. Since 1985, however, blood donations have been screened for the presence of the AIDS virus. According to the National Academy of Sciences' Institute of Medicine (IOM), a vaccine is not expected to be developed for at least five years and probably longer. None of the treatments developed so far cure the disease, although at least one, azidothymidine (AZT), may prolong life.

AIDS is caused by the human immunodeficiency virus (HIV). Although persons infected with HIV may not show any clinical symptoms of AIDS for months or even years, they may never become free of the virus. Unfortunately, this complicates controlling the spread of the virus because those infected with HIV, but having no symptoms, may infect others without realizing it. Individuals infected with HIV produce antibodies to the virus, which can be detected through blood tests. These antibodies, which are ineffective in protecting the body from developing AIDS, are usually produced within 6 to 8 weeks of exposure to the virus. Presence of antibodies in the blood, or seropositive HIV antibody status, indicates that an individual has been infected with the virus, not that he or she has or will contract AIDS.

According to the Centers for Disease Control (CDC), a part of the Public Health Service (PHS) within the Department of Health and Human Services (HHS), an individual is considered to have AIDS if a blood test indicates the presence of antibodies to the AIDS virus and he or she has one or more debilitating and potentially fatal bacterial, protozoal, or fungal infections. The two most common infections contracted by AIDS patients are pneumocystis carinii pneumonia and Kaposi's sarcoma. CDC recently broadened the definition of AIDS to include two other common AIDS conditions--severe weight loss (wasting) and neurological impairment adversely affecting intellectual capacity (dementia). An individual who has been exposed to the AIDS virus and has developed one or more of these conditions, such as chronic swollen glands, recurrent fevers, unintentional weight loss, lethargy, and minor alterations of the immune system (less severe than those in patients with AIDS) is considered to have AIDS-related complex, which can also be debilitating or fatal.

CDC estimates that there may be eight cases of AIDS-related complex for every case of AIDS.

Epidemiology of AIDS

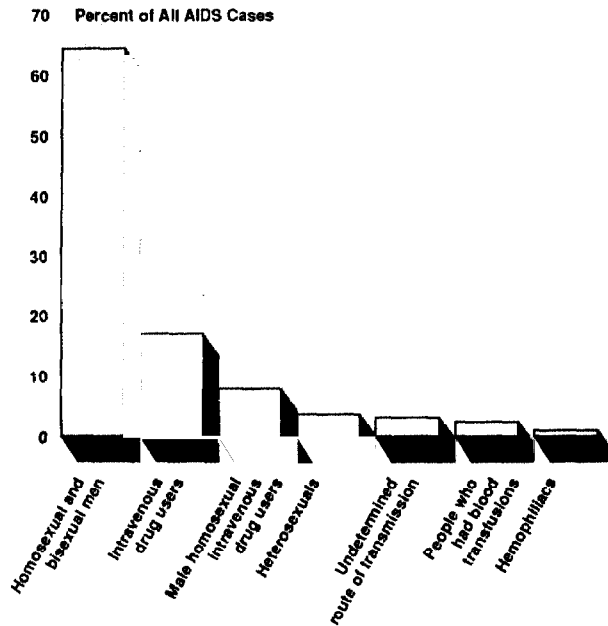
After epidemiologists identified the first AIDS cases in 1981, public health surveillance of the epidemic has resulted in data that are essential to the understanding of the prevalence and spread of the disease. By September 1982, CDC had established its definition of AIDS, and a CDC-organized national surveillance system was in place. Since 1983, when most states began reporting AIDS to public health officials, the surveillance system has helped to chart the growing magnitude of the epidemic, delineate its occurrence in major risk groups, and monitor the geographic patterns of the disease.

Since 1981, when about 300 cases of AIDS were reported, the caseload has grown to nearly 38,000. As of June 1987, over 21,000 Americans have died of CDC-defined AIDS. Figure 1 shows the distribution of AIDS cases as of June 1987 among the following groups:

- homosexual and bisexual men, 66.1 percent;
- present or past IV drug users, 16.4 percent;
- male homosexual IV drug users, 7.6 percent;
- heterosexuals, 3.9 percent;
- undetermined route of transmission, 3.0 percent;
- persons who have had transfusions with contaminated blood or blood products, 2.1 percent; and
- persons with hemophilia or other blood clotting disorders, 0.9 percent.

Nearly half the adult cases are in persons aged 30 to 39 years, and 93 percent of reported AIDS cases are among men.

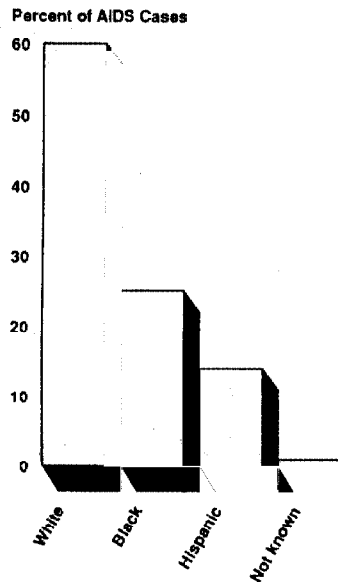
Figure 1: Types of People Who Have AIDS (1987)



Source: "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Disease Control, CDC, June 29, 1987.

Figure 2 shows the impact of AIDS by race and ethnic group. As of June 1987, 61 percent of the cases were among whites, but 24 percent were black and 14 percent Hispanic, even though these two groups represent 12 percent and 6 percent of the U.S. population, respectively. (The remaining 1 percent were of unknown race or ethnic origin.) Moreover, of all AIDS cases in children, 53 percent were black and 25 percent Hispanic. In addition, as of July 6, 1987, 410 children had been born with AIDS, according to a CDC researcher. Of these pediatric cases, 73 percent were related to IV drug-using parents--56 percent from mothers who were IV drug users and 17 percent from IV drug-using fathers who passed the virus to the mother, who in turn infected the newborn child.

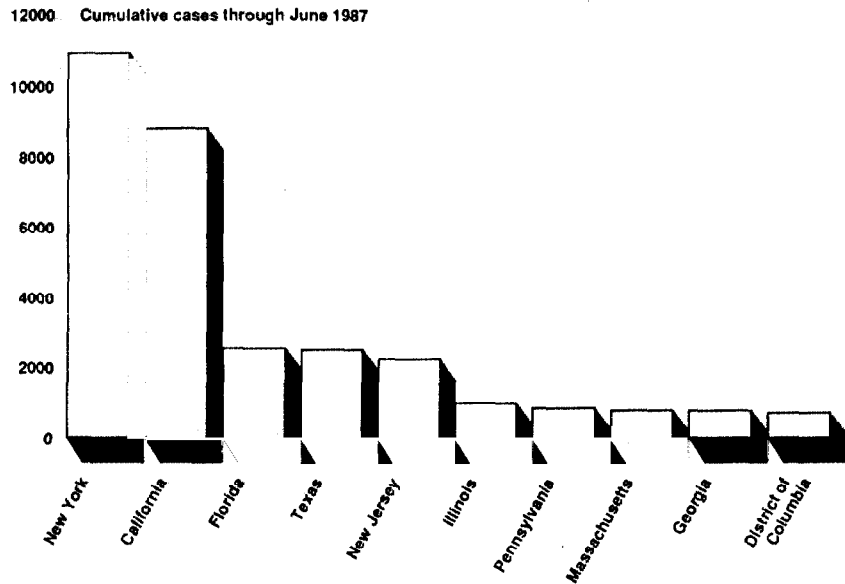
Figure 2: Distribution of AIDS Cases by Race and Ethnic Origin (1987)



Source: U.S. Public Health Service.

The highest cumulative numbers of AIDS cases have been reported in New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, Massachusetts, Georgia, and the District of Columbia (see fig. 3). Between June 1986 and June 1987, the rate of increase in reported cases ranged from 8 percent in New York to 128 percent in Texas. In New York City, AIDS has been the leading cause of death for males aged 30 to 39 years since 1984, and it was recently reported as the number one killer of females in New York City between the ages of 25 and 34 years.

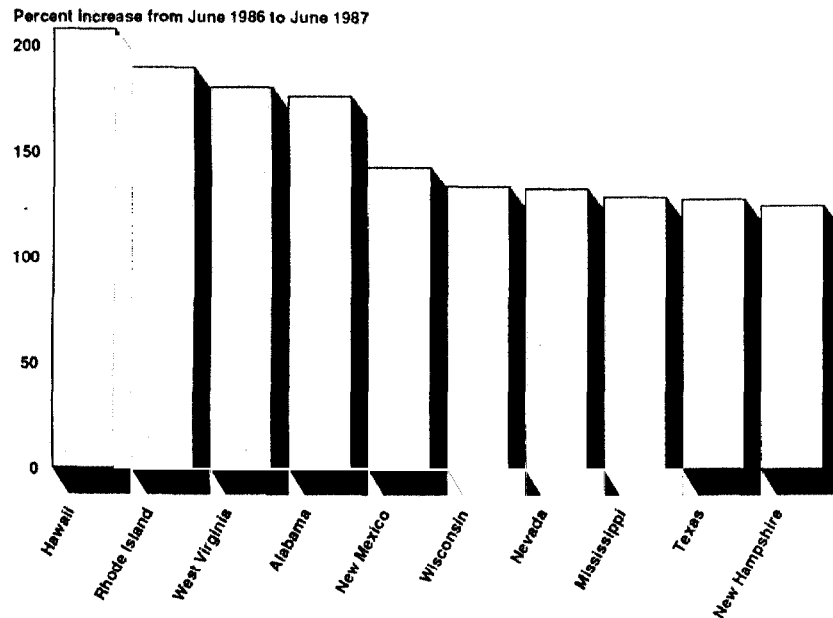
Figure 3: States With the Greatest Number of AIDS Cases (1987)



Source: "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Disease Control, CDC, June 29, 1987.

CDC data show that HIV infection and AIDS are also increasing in other states at a rapid rate. Figure 4 shows that in states with relatively few AIDS cases, the rate of increase between June 1986 and June 1987 exceeded 150 percent in four states and 100 percent in six states. By 1991, PHS expects 80 percent of AIDS cases to occur in areas outside of New York City and San Francisco. Furthermore, the proportion of AIDS cases among heterosexuals has increased from 3.5 percent in 1986 to about 4 percent in 1987, and is projected to reach 5 percent by 1991.

Figure 4: States With the Greatest Increase in AIDS Cases (1987)



Source: Computed from "AIDS Weekly Surveillance Report," AIDS Program, Center for Infectious Disease Control, CDC, June 29, 1987.

According to IOM, epidemiologic and surveillance efforts show that HIV infection is far more common than AIDS. As of June 1986, CDC estimated 1 to 1.5 million Americans were infected with HIV. Studies of the prevalence of HIV in blood samples can document the continuing spread of the virus in known high-risk groups and monitor the potential spread to heterosexuals. By measuring the extent of HIV infection before and after preventive intervention, it may be possible to assess the effectiveness of programs designed to limit its spread. If persons reduce their risk of exposure by changing their behavior, for instance, the rate of infection should be lower.

While infection with HIV does not always lead to AIDS, the probability that it will is not easily dismissed. PHS estimated that 20 to 30 percent of those infected might develop AIDS; however, new epidemiologic research suggests that more than 50 percent will eventually develop AIDS. These percentages do not include the number of persons with AIDS-related complex because reporting of these cases has not been required, in part because there is no nationally accepted definition.

Costs of AIDS

The costs of treating AIDS appear to vary across the nation. Most studies in the literature have focused on the direct costs associated with hospitalization. According to the Office of Technology Assessment, reports of hospital costs over the lifetime of an AIDS patient have ranged from about \$25,000 to \$147,000. The available studies, however, may understate costs. Because of data limitations, most studies we reviewed exclude the cost of services received outside the hospital, such as drugs, institutional or home-based long-term care, hospice care, ambulatory physician and ancillary services, counseling, and community support services. Moreover, no estimates of the costs associated with AIDS-related complex or other HIV-related conditions are available.

The most comprehensive and rigorous study of national costs of AIDS was done by Scitovsky and Rice¹ for CDC. Using an average annual cost of medical expenses at nearly \$36,000 and average lifetime hospital costs of \$60,000 and \$75,000 per case, the authors estimated 1986 direct costs for personal medical expenditures at \$1.1 billion and projected that these direct costs would reach \$8.5 billion in 1991. (For comparative purposes, 1991 health costs associated with auto accidents have been estimated by others at \$8.0 billion; digestive cancers, \$4.9 billion; lung cancer, \$3.9 billion; kidney disease, \$3.2 billion; and breast cancer, \$3.1 billion.) These AIDS costs represented 0.2 percent of total personal health care expenditures in 1985, estimated to reach 1.4 percent in 1991. The authors also estimated the indirect costs associated with losses in productivity generally reflecting the premature death of working-age adults. These costs, estimated at nearly \$4 billion in 1985 and \$55.6 billion in 1991, greatly exceed the direct medical costs of treating AIDS.

Considerable uncertainty surrounds these estimates, however. The key factor is uncertainty about the future course of the epidemic, which makes forecasting future costs extremely difficult. For example, a recent study by the Rand Corporation² uses the CDC figures of 220,000 new cases between 1986 and 1991 as a low-range estimate and projects costs for possible caseloads of 400,000 and 750,000 during the same period. Based on these

¹Anne Scitovsky and Dorothy Rice, "Estimates of the Direct and Indirect Costs of Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991," Public Health Reports, vol. 102, no. 1 (Jan.-Feb. 1987), pp. 5-16.

²Anthony Pascal, The Costs of Treating AIDS Under Medicaid: 1986-1991 (Santa Monica, Calif.: The Rand Corporation, May 1987).

prevalence estimates, the study projects cumulative treatment costs for the period 1986-91 could increase to almost \$38 billion. Using the most pessimistic assumptions about increasing prevalence, these costs could approach \$112 billion.

Two other important variables also affect the cost estimates. First, the distribution of cases of AIDS and AIDS-related complex by diagnosis may change over time. This may raise or lower costs. For example, according to CDC, the proportion of AIDS patients with Kaposi's sarcoma may decrease while pneumocystis carinii pneumonia may increase. Since the latter is more expensive to treat, direct personal medical costs would be expected to rise. Other changes in case-mix may also raise or lower total treatment costs. Second, changes in medical treatment are constantly occurring, particularly in high-incidence cities. For example, there is evidence that the average length of hospital stays is declining as outpatient diagnosis and treatment practices develop. Moreover, therapeutic interventions such as AZT affect the costs of treating AIDS in two ways--by raising pharmaceutical costs and by changing the clinical course of the disease. Patients on this drug may live longer, but require a different mix of treatment services. This may in turn raise or lower treatment costs. In addition, drugs like AZT may improve the quality of life and lessen productivity losses if AIDS patients can continue to work longer than would have been possible without the drug.

Federal Expenditures for AIDS

Federal spending on AIDS research and prevention has increased dramatically since 1981 when AIDS was first identified. By fiscal year 1988, the proposed federal PHS budget for AIDS increased to more than \$790 million and expanded funding to six PHS agencies--the National Institutes of Health (NIH); CDC; the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); the Food and Drug Administration (FDA); the Office of the Assistant Secretary for Health (OASH); and the Health Resources and Services Administration (HRSA).

In each fiscal year since 1983, the Congress has increased the AIDS budget by 76 percent to 115 percent over the previous year. Congressional appropriations have consistently exceeded the administration's budget requests, according to the Congressional Research Service.

As table 1 shows, PHS's annual expenditures have increased from \$200,000 in fiscal year 1981, to over \$790 million budgeted for fiscal year 1988.

**Table 1: PHS Expenditures/Budgets
for AIDS, Fiscal Years 1981-88**

Dollars in thousands

| <u>Year</u> | <u>Amount</u> |
|-----------------|---------------|
| 1981 (Actual) | \$ 200 |
| 1982 (Actual) | 5,555 |
| 1983 (Actual) | 28,736 |
| 1984 (Actual) | 61,460 |
| 1985 (Actual) | 108,618 |
| 1986 (Actual) | 233,812 |
| 1987 (Estimate) | 447,375 |
| 1988 (Proposed) | 790,661 |

Source: U.S. Congressional Research Service, Federal Funding for AIDS Research, Washington, D.C. (Feb. 2, 1987), p. 9 and HHS.

In recognition of the need for increased funding, the administration's current fiscal year 1988 budget request for AIDS is almost 50 percent larger than that proposed in the President's 1987 budget for PHS. Table 2 shows by agency the proposed PHS budget request for fiscal year 1988.

**Table 2: PHS Budget Requests for AIDS,
Fiscal Year 1988**

Dollars in thousands

| Research | | | |
|--------------------|-----------------------|-------------------------|------------------------|
| <u>Agency</u> | <u>Budget request</u> | <u>Budget amendment</u> | <u>Current request</u> |
| FDA | \$ 12,238 | \$ 7,280 | \$ 19,518 |
| CDC | 40,133 | 14,000 | 54,133 |
| NIH | 331,668 | 72,898 | 404,566 |
| ADAMHA | <u>28,326</u> | <u>12,725</u> | <u>41,051</u> |
| Subtotal | <u>412,365</u> | <u>106,903</u> | <u>519,268</u> |
| Prevention | | | |
| HRSA | 6,600 | - | 6,600 |
| CDC | 69,001 | 107,500 | 176,501 |
| NIH | 1,672 | 1,472 | 3,144 |
| ADAMHA | 26,091 | 34,110 | 60,201 |
| OASH | <u>800</u> | <u>-</u> | <u>800</u> |
| Subtotal | <u>101,164</u> | <u>143,082</u> | <u>247,246</u> |
| Other ^a | | | |
| FDA | 3,452 | 1,600 | 5,052 |
| CDC | 3,377 | - | 3,377 |
| NIH | 10,528 | 4,190 | 14,718 |
| OASH | <u>-</u> | <u>1,000</u> | <u>1,000</u> |
| Subtotal | <u>17,357</u> | <u>6,790</u> | <u>24,147</u> |
| Total | <u>\$533,886</u> | <u>\$256,775</u> | <u>\$790,661</u> |

^aPrevention of transfusion-related AIDS, development and evaluation of blood tests, and patient care and health needs at FDA, CDC, NIH, and OASH.

In addition to PHS's funding for AIDS, other federal programs and departments are involved in screening for AIDS, providing medical care to AIDS victims, or paying benefits to people who become eligible because of the disease. AIDS patients may qualify for Social Security Disability Insurance, Medicare, and, in some circumstances, for Supplemental Security Income benefits. They may also be eligible for Medicaid, a federally aided, state-administered program of medical assistance for low-income persons. In addition, the Veterans Administration and the Department of Defense provide medical care to AIDS patients.

The Department of Defense also screens current personnel and recruits for evidence of AIDS infection and provides treatment. Other executive branch agencies have also established testing programs. The Department of Labor has established a system for screening current Job Corps enrollees and new applicants, the State Department requires testing for assignment to the Foreign Service, and the Department of Justice has ordered testing for federal prisoners. Table 3 shows the approximate amounts to be spent by other agencies in fiscal year 1988 on AIDS.

Table 3: Estimated Federal Expenditures for AIDS Other Than From PHS, Fiscal Year 1988

Dollars in millions

| <u>Program or Department</u> | <u>Estimated amount</u> |
|--------------------------------------|-------------------------|
| Health Care Financing Administration | |
| Medicaid federal share | \$300 |
| Medicare | 15 |
| Social Security | 48 |
| Veterans Administration | 67 |
| Department of Defense | 52 |
| Department of Labor | 1 |

Source: U.S. Office of Management and Budget and Health Care Financing Administration.

Other federal programs less directly related to AIDS prevention or treatment may also have an effect on the overall effort. For example, to the extent that the Department of Justice's law enforcement activities are effective in reducing the population of IV drug users, their transmission of AIDS should also decline.

OBJECTIVES, SCOPE, AND METHODOLOGY

The Chairman of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Senate Committee on Appropriations, asked us on June 16, 1987, to review the adequacy of and justification for the proposed PHS budget for AIDS in fiscal year 1988. During discussions with the Chairman's office, we agreed to obtain the views of experts who have a nationwide perspective on the AIDS epidemic, state and local health officials in areas of the country with the most experience with

AIDS, and advocacy groups concerned about AIDS. We asked such individuals (1) whether the proposed AIDS budget priorities were appropriately set; (2) what increases, if any, were needed to help slow the further spread of infection; and (3) how additional resources, if available, should be allocated among competing prevention priorities.

After reviewing the literature, including IOM's 1986 report on AIDS,³ and interviewing federal officials and other experts, we identified education targeted at both high-risk groups and at the general public and testing and counseling services as priority areas for AIDS prevention. We then asked budget officials at PHS to provide funding levels for each priority area in the fiscal year 1988 budget. Following this, we interviewed experts (see app. I) from professional organizations, advocacy groups, and state and local health departments to obtain their views on the priorities and adequacy of funding in the administration's proposed budget. The views reported are those of the individual experts we interviewed, not necessarily those of the organizations with which they are affiliated.

At the request of the Subcommittee, we contacted experts who served on the Committee on a National Strategy for AIDS, convened by IOM. We also interviewed officials at the American Medical Association (AMA), which recently developed a policy position paper on AIDS. Finally, we met with experts at advocacy groups and state and local health departments in high-incidence cities because they have had the most experience with trying to contain the AIDS epidemic. We visited New York City, San Francisco, Los Angeles, Miami, Chicago, and Boston. We also asked state and local health departments (1) what their priorities are for prevention programs, (2) what they are currently spending on these activities, and (3) how they would allocate additional resources among their prevention programs.

Our work was done in June and July 1987 and in accordance with generally accepted government auditing standards.

**PRIORITY AREAS AND ESTIMATED
BUDGET SHORTFALLS FOR AIDS
PREVENTION RESOURCES**

We identified three major prevention areas included in the proposed budget--(1) reducing HIV infection among IV drug users and their sexual partners, (2) educating targeted high-risk groups and the general public, and (3) expanding the availability of voluntary testing with pretest and posttest counseling

³Institute of Medicine, National Academy of Sciences, Confronting AIDS: Directions for Public Health, Health Care, and Research (Washington, D.C.: National Academy Press, 1986).

services. The experts we interviewed generally agreed that these areas deserve high priority in federal efforts to limit the spread of AIDS.

For at least the next several years, according to IOM, the most effective measure to significantly reduce the spread of HIV infection is education of the public, especially those individuals engaging in behaviors that increase the risk of contracting AIDS. IOM emphasized that people must have information on ways to change their behavior and encouragement to protect themselves and others from infection. Moreover, education is needed for those who interact with infected persons and for those who are in a position to influence public opinion. Education serves not only to transfer knowledge but to induce, persuade, and otherwise motivate people to avoid the transmission of HIV, according to IOM.

A fifth effort broadly supported by the experts is a national study of the extent of HIV infection in a random stratified sample of persons. This would enable epidemiologists to construct a baseline and track the spread of HIV infection. There was less agreement, however, on the design and methodology for conducting such a study. (Although HHS did not request funds for such a study in the current budget, the President may direct that about \$17 million be expended to develop this information, according to HHS budget officials.)

In its 1986 report, IOM recommended that by 1990 about \$1 billion be spent annually on education and other AIDS-related public health measures. A major portion of the total, the report stated, should come from federal sources because "only national agencies are in a position to launch coordinated efforts commensurate with the potential size of the problem."

We obtained the views of AMA officials and individuals who served on the IOM Committee on a National Strategy for AIDS. They told us that resources are inadequate in all priority areas. According to their estimates, at least \$365 million more is needed for AIDS prevention programs.

MORE FUNDS NEEDED TO LIMIT SPREAD OF HIV AMONG IV DRUG USERS

As of June 1987, over 16 percent of all AIDS cases nationally were attributable to needle sharing by IV drug users. The percentage of AIDS cases related to IV drug use in high-incidence areas, however, varies from 30 percent in New York City to 2 percent in Los Angeles.

There is considerable geographic variation in the rate of HIV infection among IV drug users. For instance, in New York City, which has about one-third of the nation's 750,000 IV drug

users, more than 50 percent of IV drug users tested have been exposed to the AIDS virus; about 20 percent of IV drug users in Boston test positive; and smaller percentages of IV drug users test positive in low-incidence areas.

Current research shows that education can change behavior among IV drug users. For example, a study in New York City of IV drug users in methadone maintenance centers (programs designed to substitute methadone for heroin) indicated that they shared information on how to protect themselves. Moreover, lack of education was not a barrier to self-protective behavior because more highly educated drug injectors apparently transmitted information about protective behaviors, such as sterilizing or not sharing equipment, to their less educated acquaintances. About 60 percent of the IV drug users surveyed by researchers in New York City reported at least one behavioral change to avoid AIDS. Specific activities included using clean needles or cleaning needles (31 percent) and reducing needle sharing (29 percent). Another study in New York City showed that 97 percent of IV drug users were aware that sharing needles could transmit AIDS and, in response, 60 percent reported they had changed their drug/needle use to reduce the risk of contracting AIDS. Data from New Jersey indicated that in 1985, about half of the IV drug users entering treatment cited fear of contracting AIDS as a reason for seeking treatment.

Behavioral changes are also supported by data that are not self-reported. Specifically, persons selling needles report increased demand for clean needles. In response, a counterfeit sterile needle market has emerged, in which a used needle is resealed in its original package. Also, "free" sterile needles are now being used as a marketing tactic in the New York City heroin trade.

Proposed Budget

The proposed PHS budget targets \$70 million toward IV drug users. Of this amount, \$15 million is for testing and counseling services for IV drug users and their sex partners. The budget also includes \$55 million for AIDS education targeted at IV drug users, their sex partners, and health professionals who work with IV drug users. This money is to be administered through ADAMHA's National Institute on Drug Abuse.

These prevention activities include epidemiologic studies and outreach activities to find and educate the sex partners of IV drug users, as well as studies to measure the prevalence of HIV infection among IV drug users. Other public health control measures include

- assisting communities to develop local public information efforts;

- developing entertainment industry public information efforts;
- training health care workers who deal with IV drug users;
- funding outreach demonstration projects targeted to highly vulnerable populations, including minorities and persons not in drug treatment; and
- funding comprehensive community demonstration programs.

Funding for the comprehensive community demonstration programs was expanded by \$20 million in the fiscal year 1988 budget amendment. These demonstrations--experimental programs that furnish services to individuals--are intended to provide essential data to policymakers on the most efficient and effective delivery of services to program beneficiaries. HHS increased funding from \$5.6 million to \$16.6 million to support demonstration programs in 15 rather than 5 cities with high AIDS prevalence, and also added \$9 million to fund 8 more cities where the prevalence of AIDS is low.

Expert Views

According to the experts we interviewed, the relatively low prevalence of HIV infection in IV drug users in many parts of the country presents an important opportunity to limit the spread of infection in this high-risk group. Furthermore, since IV drug users are the primary source of transmission to heterosexuals (accounting for 60 percent of heterosexual cases) and of perinatal transmission to newborns (accounting for 73 percent of pediatric cases), containing the epidemic in this group could have a major impact on the projected caseloads in the general population.

All the experts we interviewed from IOM's Committee on a National Strategy for AIDS and state and local health department officials cited the epidemic in IV drug users as a dangerous and alarming problem because of the potential spread from this group to the heterosexual population. This threat resulted in the experts giving priority to IV drug users in both high- and low-incidence areas. Moreover, according to experts in New York City, the proposed budget of \$70 million is deficient because it does not include funds for drug abuse treatment--methadone (for heroin users) and detoxification programs--targeted to the AIDS problem. Officials in New York City estimated that they could spend \$50 to \$150 million to expand drug treatment programs.

According to IOM's report, the availability of treatment for IV drug users was less than demand even before the AIDS epidemic. New York City officials told us that IV drug users may wait for

up to 2 months for treatment. Nationally, existing resources may be sufficient to treat about 20 percent of IV drug users. Without sufficient treatment capacity to help drug users avoid the use of hypodermic needles, education and outreach efforts will have greatly reduced effect, according to the experts.

On a purely economic level, IOM found that treating drug users is cost-effective. They compared methadone treatment costs of about \$3,000 per year with potential annual costs of at least \$50,000 to treat AIDS patients. In New York City, experts told us that "no frills" methadone treatment--dispensing methadone with crisis intervention counseling, but without elaborate mental health and social worker intervention--could cost as little as \$1,500 per case per year. They said, however, that current federal regulations require extensive counseling as an integral part of drug treatment at methadone centers. Residential drug-free treatment program costs were higher at about \$12,000 per person per year.

IOM's report also recognized that not all IV drug users will be persuaded to substitute methadone for heroin or to stop injecting drugs. Therefore, the report recommended experimenting with the removal of legal restrictions on the sale and possession of sterile hypodermic needles and syringes. This would give IV drug users who do not want to enter treatment the opportunity to reduce their risk of acquiring or transmitting AIDS. Several states have attempted to take such action, but they have generally been opposed by law enforcement officials who believe the availability of drug-injecting equipment will lead to more drug use.

In New York City, 30,000 of the estimated 200,000 IV drug users are in treatment at an annual cost of about \$150 million in fiscal year 1987. (About 15 percent was federally funded.) To double the number of patients receiving treatment without building additional facilities, an additional \$50 million would be needed, according to state officials. City officials added that existing clinics would not be able to handle such an increase, and that adding capacity might increase costs to about \$150 million. In Boston, where there are an estimated 13,000 persons injecting illegal drugs, about 2,300 are in treatment at an annual cost in fiscal year 1987 of \$5.8 million. Boston hopes to double its resources in this area in fiscal year 1988, but would still fall far short of its goal of reaching 10,000 IV drug users. Officials in Boston and San Francisco also indicated that they need additional federal funds to expand methadone treatment. City officials in San Francisco told us that they are currently spending about \$340,000 for prevention programs targeted to all substance abusers, not just those who inject drugs. They contend that more funding for this group is a critical priority.

GAO Comments

The \$50 to \$150 million in additional federal funding to limit the spread of HIV among IV drug users is based only on estimates of funds needed to expand methadone treatment in New York City, which accounts for about one-third of the nation's IV drug users. Funds may be available elsewhere in the federal budget (such as over \$250 million for the Anti-Drug Abuse Act of 1986) that could be designated in part for drug treatment aimed at AIDS prevention.

Many social, political, and financial barriers preclude expansion of drug treatment programs and other measures aimed at IV drug users. For instance, most communities resist placement of methadone maintenance clinics in their neighborhoods. While treatment programs for IV drug users would be the preferred option to preventing AIDS, rapid expansion over the next few years will be expensive. In the interim, less expensive methods of reducing the spread of HIV infection that do not require changing drug users' basic behavior, such as teaching drug users how to disinfect needles, could be implemented. Moreover, these methods of prevention can be used for all IV drug users, not just the heroin-injecting population.

The HHS budget amendment increases funding for drug users in low-incidence areas. As recommended by the IOM report, delaying public health education efforts in low-incidence areas until cases occur increases the probability that the AIDS problem in such areas will become much worse. For this reason, this opportunity to forestall the further spread of infection will mean larger expenditures now, but may result in substantially lower treatment expenditures within the next few years.

MORE FUNDS AND HEIGHTENED SENSE OF URGENCY NEEDED FOR EDUCATION

In its 1986 report, IOM said that AIDS education should be pursued with a sense of urgency and level of funding that is appropriate for a life-or-death situation. Greatly expanded educational programs to effect behavioral change are necessary, according to IOM, for both high-risk groups, minorities, and the general population. Moreover, to effectively control the spread of HIV infection, education must start or be expanded immediately, not only in areas where there are now AIDS cases but also in areas where there are as yet few or no cases.

The IOM report also pointed out the expense involved in newspaper, radio, and, particularly, television advertising. For example, one page of advertising in a major newspaper can cost about \$25,000 per day, and a minute of national television time can cost between \$60,000 and \$400,000. The report concluded that policymakers must be prepared to spend at the same level as

private sector companies do to influence behavior. Further, it was recommended in the report that the legal provisions which prevent CDC from paying for advertising be altered by the Congress to permit greater access through the medium than public service announcements, which are aired during prime time at the discretion of the networks.

Media campaigns about AIDS will require more effort and will need to be sustained over time to have an impact on public behavior, according to IOM's report. Moreover, the report found that while state resources could contribute to educational efforts, a major portion of the total funds for such a campaign should come from federal sources because only national agencies can launch coordinated efforts commensurate with the unprecedented threat of the AIDS epidemic.

The IOM report also focused on education campaigns targeted at specific groups--homosexual men, IV drug users, prostitutes, minorities, and sex partners of those in high-risk groups. The report found that efforts to inform homosexuals about the relationship between AIDS and high-risk sexual behaviors have generally been conducted and funded by homosexuals through voluntary activist organizations. Although there is evidence that many homosexuals in high-incidence urban areas have changed their sexual practices to reduce the risk of contracting AIDS, men who are bisexual or not openly homosexual may not be reached by campaigns run by such organizations. IOM's report warns that it is therefore important to communicate broadly the message that specific, high-risk sexual practices increase the probability of AIDS transmission.

Because the virus can be spread through unprotected heterosexual intercourse, according to the IOM report, clear and direct messages about transmission routes and safer sexual practices are of paramount importance to preventing the spread of the HIV infection in the general public. Bisexuals and IV drug users are the major sources of spread from high-risk groups to heterosexuals. Prostitutes are an important route of transmission among heterosexuals, with infection rates estimated at 11 percent nationally. Rates as high as 57 percent have been reported in some areas, however.

The IOM report also stated that blacks and Hispanics comprise a disproportionately high percentage of AIDS cases. Forty-five percent of these cases are in New York City. As of June 1987, 25 percent of reported cases were among blacks and 14 percent were Hispanic, demonstrating a disproportionate impact on these groups, as discussed on page 9. Among adult heterosexual men and women with AIDS, 72 percent were black or Hispanic.

Seventy-nine percent of pediatric cases have occurred in minority children at a rate 14.3 times greater in blacks and 7.4 times greater in Hispanics than whites.

An estimated 1.0 to 1.4 percent of the black population may be infected with HIV, a rate estimated to be three times that of whites. Public health researchers recommended that culturally sensitive educational messages be developed to reach minorities, and that federal agencies collect data that document differences in AIDS among minorities. These data would provide a basis for health care planning and public policy development. The IOM report also stressed the importance of specially focused programs for minorities.

The IOM report and state and local health department officials we spoke with also cited education of school-aged children as a top priority prevention activity. Surveys of high school students reveal an alarming degree of misinformation about AIDS, according to IOM. As late as 1986, even students in San Francisco were seriously misinformed about routes of transmission and preventive practices. Specifically, 40 percent did not know that AIDS is caused by a virus or that the use of a condom during sexual intercourse decreases the risk of transmitting HIV infection.

Proposed Budget

The proposed PHS fiscal year 1988 budget request includes \$155 million for education targeted at specific risk groups. This includes budget amendment increases over the original request targeted at high-risk groups--an additional \$31.5 million for IV drug users, \$9 million for school-aged children (especially in high-incidence cities), and \$10 million for minorities. Total proposed spending for educating targeted groups, therefore, is

- \$55 million for IV drug users (\$9 million to be expended in eight cities with low AIDS prevalence), as discussed in the previous section;
- \$29 million for the general population;
- \$21 million for schools;
- \$21 million for health care workers;
- \$20 million for other high-risk groups, including \$13 million for minorities; and
- \$9 million for other education efforts.

The fiscal year 1987 budget included about \$23 million for education of the general public, and the 1987 supplemental budget request added \$20 million for this purpose. The Secretary of HHS proposed that the \$20 million be reprogrammed and spent to alert the public about ways to stem the spread of AIDS, for example, through a mass mailing to all Americans or other educational efforts. Discussions within the administration about how best to inform the public and what messages to convey, however, have delayed the effort to educate the general public.

Expert Views

Both the experts from the IOM Committee on a National Strategy for AIDS and AMA concurred with the priorities reflected in the proposed budget. They told us, however, that the administration's budget request of \$155 million does not provide sufficient funding for education of either the general public or targeted groups. The experts from the IOM committee we interviewed said that at least \$100 million--about \$70 million more than the budget request--was needed to launch a massive educational campaign aimed at the general public on how AIDS is spread. AMA representatives suggested increasing AIDS education aimed at the general public and high-risk groups, especially school-aged children and health care workers, by three to five times over the fiscal year 1987 spending level. This would amount to increases of about \$65 to \$215 million for fiscal year 1988.

The experts who served on the IOM committee also expressed frustration about weak federal leadership and the lack of a sense of urgency in the education arena. They told us that this is at least as troublesome as shortfalls in the budget. Similarly, health department officials in New York City told us that they are as concerned about the lack of leadership from the federal government as they are about inadequate funding. They were particularly concerned that the federal government develop messages and convey them to the public about the gravity of the epidemic and how they can protect themselves. This would free state and local health departments to tailor messages to their own populations.

Officials in state and local health departments expressed growing concerns about AIDS in minorities. In Los Angeles, for example, many activities are targeted at the Hispanic community. In Boston, about 21 percent of new clients contacting the AIDS Action Committee (a volunteer organization offering social services to AIDS patients) were from minorities. Officials in New York City also cited minority education as a priority item. They said that although New York City has 45 percent of all minority AIDS cases, the city is eligible for only 5 percent of federal grant money for minority education because the maximum award to any location is capped at \$300,000.

The IOM report, members of the IOM committee we interviewed, and state and local health officials also urged that an evaluation component be integrated into education programs; thus the impact of these efforts on controlling the epidemic could be assessed. According to the report, a massive and decentralized education effort will have many unique elements tailored to local situations. The learning process may be slow, with considerable trial and error to determine what works. Therefore, to learn from experience, improve programs, and channel money to more effective methods of education, it will be important to design rigorous evaluations as integral parts of education efforts. Moreover, if assessments of the impact of education on the spread of the epidemic show that it is not sufficiently slowed, then additional or redirected funding for prevention measures may be necessary.

GAO Comments

Education has been shown to be effective in changing the behavior of people who are at high risk of HIV infection. In particular, education on ways to reduce risk associated with certain lifestyles makes sense because people can modify their behaviors to reduce their chances of contracting AIDS. IV drug users, for instance, can stop sharing needles. Likewise, people with multiple sex partners can reduce their risk of contracting AIDS by using condoms.

Mass media educational and advertising campaigns designed to change behavior can be expensive, especially if paid television advertising is used. The Department of Defense, for example, spent about \$180 million in fiscal year 1987 for magazine and television advertising directed at new recruits and reservists. Although CDC's costs would be lower if it continues to rely on public service announcements, the effectiveness of these ads will be reduced if they are not aired during prime viewing time.

As an alternative to having the government pay commercial rates to have public service announcements aired during prime viewing hours, television and radio stations might be encouraged to broadcast such announcements during prime time. Similarly, an alternative to paid newspaper advertisements might be notices posted on public transportation. We believe such messages could be more effective than a one-time mass mailing because they would provide a constant reminder of the threat of AIDS. In addition, a mass mailing may not reach many high-risk individuals, such as IV drug users who often may not have permanent addresses.

Many experts are looking to the federal government for at least a major portion of funding for educational efforts. Although our scope of work did not allow us to research other options in depth, we believe educational funds should come from

other sources as well as from the government. For example, life and health insurance companies will have large outlays in the next few years if the AIDS epidemic goes unchecked. Health insurance costs will increase substantially, and many death benefits will be paid prematurely. Insurance companies and others in the private sector have strong financial incentives to become involved in AIDS educational efforts.

**MORE FUNDS NEEDED TO EXPAND VOLUNTARY
TESTING AND COUNSELING SERVICES**

In March 1986, CDC published specific recommendations regarding behavior to reduce sexual and IV drug-related transmission of HIV. CDC recommended that counseling and voluntary blood testing be routinely offered to all persons at increased risk who seek treatment at certain health care settings, such as sexually transmitted disease clinics and clinics for treating drug abuse.

Based on its February 1987 conference on antibody testing and subsequent meetings with state and local health officials and epidemiologists, CDC suggested that persons in certain groups would benefit most from testing and counseling since they are most likely to be infected. These groups include

- persons seeking treatment for sexually transmitted diseases (3 to 5 million);
- persons seeking treatment for or with a history of IV drug use (750,000);
- persons who consider themselves at risk of HIV infection for whatever reason (unknown);
- women of childbearing age at risk of infection or seeking family planning services in very high and moderate prevalence areas (more than 1 million); and
- certain patients who received transfusions of blood or blood components between early 1978 and mid-1985 (10 to 12 million), especially those who received multiple transfusions from blood collected in areas with a high AIDS incidence (unknown percentage of total transfused population).

CDC also recommended that persons considering or planning marriage should have ready access to voluntary premarital counseling and testing, and informational and educational materials about AIDS and HIV infection.

The CDC recommendations for testing and counseling assume the existence and application of standards for conducting HIV antibody pretest and posttest counseling in testing centers and

established procedures to ensure that specific consent of individuals tested is obtained and confidentiality is protected. According to CDC, assuring confidentiality means that information regarding the entire process of HIV antibody testing is known only to those health care personnel who have a legitimate need for or access to the information because of their role in providing care for that person or in protecting the health of others associated with that person. CDC also suggested that if confidentiality cannot be assured, procedures allowing anonymity should be available as an option for those who would otherwise be deterred from testing.

Workshop panels at CDC's February 1987 conference also concluded that mandatory testing, other than for screening donated blood and plasma, should not be required for the prevention and control of HIV infection and AIDS. The panelists believed that most mandatory testing programs would not reach the populations at highest risk of infection and would therefore not be highly effective, that resources required for these programs might be diverted from programs with higher potential impact, and that mandatory testing might cause persons who did not wish to be tested to avoid seeking care. The summary of the CDC workshop also showed that the costs of testing large numbers of people at low risk would be high relative to the benefits obtained. For example, CDC estimated the costs of detecting one infected person in a low-incidence population (0.1 percent) at over \$18,000 per person identified, while the costs of detecting an infected person in a high-incidence population (20 percent) dropped to about \$130 per person.

CDC described the financial and personnel resources necessary to establish effective HIV antibody counseling and testing programs. According to CDC, state and local health officials most frequently cited an average cost of \$45 per person for counseling and testing, although such services were estimated to be more than twice as high in some areas. About half the costs were for laboratory expenses and half for counseling. Pretest counseling of 15 minutes cost about \$4. Posttest counseling for an individual who has not been exposed to HIV costs about \$11 for 45 minutes, while costs for an individual who has been exposed rise to about \$22 for a 90-minute counseling session.

CDC added that these estimates do not reflect the additional costs of referring and counseling sex partners, training and supervising new counselors, and increasing laboratory and support capabilities and quality assurance programs necessary for expanded services. Other costs not reflected involve developing and distributing educational materials that will be needed for people who are not fluent in English, have different educational levels, or have other cultural backgrounds that may require specially targeted information to intervene effectively.

Proposed Budget

The fiscal year 1988 budget includes \$92 million for testing and counseling services. Of this, \$15 million is earmarked for determining the rate of HIV infection in IV drug-using populations. The remaining \$77 million is intended for expanding state counseling, testing, and partner referral services, particularly for high-risk individuals. Such services have been provided in about 1,100 testing sites across the nation.

The budget for testing and counseling services represents, according to HHS, about half of the resources expended by the states. Therefore, HHS anticipates that national spending on such services would approach about \$184 million.

Expert Views

AMA recommended that testing capacity be increased by three to five times, citing unacceptable waiting periods at test sites in Chicago. Officials in other cities we visited told us that individuals typically had to wait several weeks to be tested. The experts we interviewed also believe that general education campaigns will probably increase demand for testing services. They expressed concerns that many who may request testing as a result of media campaigns may be at relatively low risk, and that these individuals may saturate the capacity for testing. They also told us that mandatory testing would divert resources from high-risk persons to populations with a relatively low risk of infection.

GAO Comments

HHS estimates that the revised federal budget provides funds for about half the counseling and testing needed nationwide. Using an average cost per test of \$45, we estimate the federal budget matched with state funds would cover testing and counseling services for about 4 million individuals. According to IOM's report, however, more than 10 million persons may be candidates for testing. Recent CDC data on the estimated populations at high risk of HIV infection--homosexual/bisexual men, IV drug users, and heterosexuals at high risk--approach 10 million persons. At an average cost of \$45 per person, potential resources needed if these individuals request testing would approach \$450 million. Assuming federal and state resources of about \$184 million, over \$250 million more in funding would be needed to meet this demand.

Experts we contacted at CDC and IOM were unable to predict the potential demand for testing from either high-risk individuals or the general public. Using CDC's estimates of the size of potentially high-risk populations, however, we estimate costs for testing and counseling of \$180 million for persons

seeking treatment for sexually transmitted diseases, \$34 million for IV drug users, and \$45 million for pregnant women in high- and moderate-prevalence areas. Many of these individuals may need to be tested periodically. Additional costs would also be incurred for heterosexuals who perceive themselves to be at risk for whatever reason, persons who received blood transfusions before screening of the blood supply was implemented in 1985 (especially those receiving multiple transfusions in high-incidence areas), and prostitutes. Moreover, intensive educational campaigns may increase demand for testing in relatively low-risk populations. Precise budgetary needs, therefore, are difficult to predict.

Individuals' knowledge of their HIV antibody status and counseling is important so that they can take steps to avoid infecting others. Testing and counseling must be used judiciously, however, because the cost of identifying an infected person in a low-incidence population is much greater than in a high-incidence population.

PERCEIVED LACK OF FEDERAL LEADERSHIP

The experts also expressed concern about the perceived lack of federal leadership. Members of the IOM committee and state and local health department officials in New York City, Boston, and San Francisco told us that the patchwork of federal and state funding available for AIDS prevention programs and the lengthy and cumbersome application processes for grants have prevented a quick response to the AIDS epidemic in many instances. Some state officials said they would rather have less money than more money with federal strings attached. Others were frustrated because public health educators on their staffs and other professionals were spending inordinate amounts of time responding to requests for proposals or applying for other sources of funding instead of educating the community about AIDS.

These concerns reflect the federal response to AIDS within the context of current health policymaking in general and the limited role of the federal government in domestic social programs in particular, according to health policy researchers.⁴ These researchers concluded that the federal response to AIDS appears uncoordinated and insufficient, particularly for public health education and financing of care for treatment of patients. They based their conclusion on systemic factors in our health care system, including (1) multiple levels of government, (2) the relationship of government to the private sector, (3) the diffusion of authority within the federal government, (4) the absence of mechanisms to deal with emergencies, and (5) the tendency to fund AIDS by reallocating funds already appropriated to other existing health programs.

⁴Philip R. Lee and Peter Arno, "The Federal Response to the AIDS Epidemic," Health Policy, vol. 6 (1986), pp. 259-67.

EXPERTS INTERVIEWED ON THE ADEQUACY OF
AND JUSTIFICATION FOR THE FISCAL YEAR 1988
AIDS PREVENTION BUDGET

Nationwide Perspective

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