

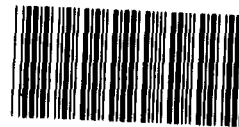
GAO

Report to the Chairman, Subcommittee
on Human Resources and
Intergovernmental Relations,
Committee on Government Operations,
House of Representatives

June 1991

AIDS-PREVENTION PROGRAMS

High-Risk Groups Still Prove Hard to Reach



144504

RELEASED

RESTRICTED—Not to be released outside the
General Accounting Office unless specifically
approved by the Office of Congressional
Relations.

GAO

Report to the Chairman, Subcommittee
on Human Resources and
Intergovernmental Relations,
Committee on Government Operations,
House of Representatives

June 1991

AIDS-PREVENTION PROGRAMS

High-Risk Groups Still Prove Hard to Reach



144504

RELEASED

**RESTRICTED—Not to be released outside the
General Accounting Office unless specifically
approved by the Office of Congressional
Relations.**

Human Resources Division

B-243374

June 14, 1991

The Honorable Ted Weiss
Chairman, Subcommittee on Human Resources
and Intergovernmental Relations
Committee on Government Operations
House of Representatives

Dear Mr. Chairman:

This report responds to your request that we review the Counseling and Testing Program designed by the Centers for Disease Control (CDC) to prevent the spread of the human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS). Of its \$443 million in 1990 HIV funds, CDC, the lead federal agency for HIV prevention, targeted about \$82 million to state and local health departments for counseling and testing services. The goal of these programs is to educate people about HIV infection, motivate them to change their risky sexual and drug-using behaviors that could lead to their own or others' infection, encourage them to be tested to determine if they are infected, and refer them for treatment if they are infected.

Expressing concern that AIDS is still spreading rapidly among groups engaged in high-risk behaviors, you requested information on the main federal initiative at CDC that might reach these groups. This report responds to many diverse questions under the three main concerns that you raised: (1) testing and counseling services were not reaching some of the highest risk groups, such as intravenous (IV) drug users; (2) monitoring and evaluation of services were not taking place; and (3) funds were not being distributed in a timely manner so that HIV prevention services could begin at the community level.

Results in Brief

First, many high-risk or infected people, specifically IV drug users, have not received counseling and testing services aimed at stopping the spread of the disease or treatment of their infection. Only about 170,000 (less than 20 percent) of the 1 million people that CDC estimates to be infected have been identified by the CDC Counseling and Testing Program since 1985, even though such services have been widely available. This is because many of those at high risk, specifically IV drug users, have not been among those 3 million tested since 1985. Some innovative, effective outreach services have been implemented in some locations,

but the IV drug users group is a difficult one to reach. Moreover, regardless of their risk, only about 40 percent of those tested returned for their test results.

Second, monitoring to oversee program activities and evaluation to assess the effectiveness of various approaches are under way. However, a new statistical database is not yet fully functional; therefore, sophisticated analyses cannot be done. Since evaluations have just recently been funded, only preliminary results are available on the effectiveness of counseling approaches.

Third, state and local health departments have improved their distribution of funds to service providers. Delays in committing funds, experienced in the initial years of the program, have been substantially reduced.

Scope and Methodology

To assess HIV counseling and testing services for people at high risk of infection, we focused on seven CDC-funded project areas: the states of California, New York, and Texas and the cities of Houston, Los Angeles, New York, and San Francisco (see app. V for a listing of the agencies and organizations we visited.) We interviewed officials, studied documents, and analyzed data. To assess CDC monitoring, we reviewed key monitoring activities and identified federally funded evaluation research projects. To assess the timeliness of funding commitments for HIV prevention and surveillance programs, we reviewed available information on financial status reports for 1986-89 relating to cooperative agreements.¹ For the funding issues, we visited five health departments: the District of Columbia and the states of Massachusetts, New York, Ohio, and Washington; in addition, we used data from a CDC report on California's HIV program.

We conducted our review between January and October 1990 in accordance with generally accepted government auditing standards.

See appendix I for background material and a description of CDC's Counseling and Testing Program. The results of our work are summarized below and presented in more detail in appendixes II through IV.

¹Cooperative agreements may include several program components, such as (1) counseling, testing, and partner notification, (2) health education and risk reduction, and (3) minority initiatives. Although this report focuses on counseling and testing services, health departments report the status of funds obligated in the aggregate, not by such individual components.

HIV Counseling and Testing Services Widely Available, but Identification of HIV Infection Slow

Less than 20 percent of Americans estimated to be infected with HIV have been identified by CDC-sponsored testing services. Although CDC-funded programs have done an estimated 3 million HIV-antibody tests since 1985, these tests have identified only about 170,000 of the estimated 1 million HIV-infected people in this country.² One reason for the low yield is that many of those tested are not at high risk (commonly referred to as the “worried well”).

Moreover, regardless of their risk, only about 40 percent of those tested return for their test results. (This return rate is based on CDC’s monitoring data, for which we identify shortcomings in the next section.) Because they do not return, these people may be unaware of their HIV status; therefore, they may not be referred to medical and long-term counseling services or be educated on the ramifications of having HIV infection or the benefits of early medical intervention.

One of the hardest high-risk groups to reach is composed of IV drug users who have shown little interest in determining their HIV status. Some outreach activities, where available at test sites, have successfully brought IV drug users to HIV counseling and testing services. But success in reaching these drug users hinges on the future availability of drug treatment and support services. To complicate matters, counseling and testing services are offered in only about 4 percent of drug treatment centers nationwide. Long-term counseling or case management services are needed for HIV-infected people identified by CDC-funded counseling and testing services.

Because it is not a treatment provider, CDC views its program responsibilities as ending with posttest counseling. For those tested and found to be HIV infected, CDC does, however, require the programs it funds to refer these people to medical and psychosocial support services. Requiring referrals by counseling and testing programs, however, does not always mean the services needed are available in the community or that the HIV infected will avail themselves of these services. The extent of posttest counseling and the availability of long-term counseling for the HIV infected varies widely between and within individual states. Health officials pointed to the need for case management services for the HIV infected, especially among the poor and IV drug users. The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 authorized

²What is unknown is how many of these tests are retests of the same people. In addition, an unknown number of people have been tested for the HIV antibody in hospitals, outpatient medical facilities, physicians’ offices, blood-donation centers, military facilities, and other settings. Some of those tested in these other settings could also have been tested previously.

several programs that would directly address these needs, but these programs were only partially funded. About \$220 million of the authorized \$875 million was appropriated. (For further details on delivery of services, see app. II.)

Progress Slow in Monitoring the Program

Monitoring includes CDC's oversight efforts for the Counseling and Testing Program; evaluation refers to CDC's assessments of the effectiveness of approaches used to change behaviors.

Little detailed information is available on the function and effectiveness of HIV counseling and testing services, particularly as they relate to changing high-risk behaviors. This is a result of the type of statistics collected; the failure to collect data on AIDS-related knowledge, attitudes, beliefs, and behaviors (KABB); and lack of program reviews. However, more than 2 years ago, CDC began to require funding recipients to submit aggregate testing data by risk group, test site, and demographic characteristics; most of these recipients have complied.

In another recent effort to collect better monitoring information, CDC has been able to convince some of its cooperative agreement recipients to voluntarily collect new data on individual cases. CDC, however, has not yet been able to use the additional individual-level, statistical data it collects voluntarily from recipients to establish a reliable national database on counseling and testing services; this database could tally HIV tests in a way that allows analysis of coverage for high-risk groups. Such analysis is vital to assessing whether counseling and testing services are reaching those at highest risk. Over the last 4 years, CDC's attempts to gain information from surveys of AIDS-related KABB have been unsuccessful. Health departments (recipients of CDC funds) have been unable to do the surveys because of resistance and fear of resistance from respondents or the local community, even though CDC has required the surveys since 1986. Finding the surveys more complex and costly than originally envisioned, CDC is no longer requiring the KABB survey and is currently working on a replacement.

Citing staff shortages as a key problem, CDC has done very few formal, on-site program reviews in individual locations. When done, these program reviews provide an in-depth assessment of an individual recipient's efforts.

Several federal agencies, including CDC, have funded research studies addressing the contribution of various counseling approaches to

behavior modification. Final results will not be available for several years, but preliminary results from some of these studies indicate that street outreach and counseling activities do contribute to reducing high-risk behaviors. (For more information on monitoring and evaluation of programs, see app. III.)

Timeliness of Fund Commitments Improving

Health departments that had received funds for HIV counseling and testing services, as well as other prevention activities, are now doing a substantially better job of distributing funds than in the beginning of the programs. Delays in hiring personnel and contracting, however, continue to cause some problems in committing funds. As a result, delivery of some services has been slowed.

Each year, CDC funds state and local health departments. Health departments do not have to pay out these funds in the budget year awarded, but the departments should, by the terms of their agreements with CDC, finalize the commitment of the funds within the budget year.

The commitment of funds by state and local health departments includes transactions—such as awarding contracts or hiring staff—that require payment during current or future budget periods. If a contract is not awarded in the budget year, the contract amount is recorded as uncommitted. Likewise, if a staff position is not filled during the budget year, the unspent salary amount is recorded as uncommitted. Generally, a health department's uncommitted funds are carried over by CDC for use in the next year, so the funds are not lost. However, uncommitted funds are of concern because they represent HIV services that were not contracted for as planned in the budget year.

Uncommitted HIV prevention and surveillance funds decreased,³ overall, from 33 percent in 1987 to 18 percent in 1989. (See app. IV for the uncommitted percentages for each health department.) This approaches the rate for similar older CDC prevention programs, such as the sexually transmitted disease (STD) program (21 percent uncommitted) and the immunization grant program (13 percent uncommitted). (For further discussion about the timeliness of funding, see app. IV.)

³CDC was unable to state the amount of funds spent solely on prevention. Therefore, our analyses refer to combined prevention funding and surveillance funding (that is, monitoring of the number of AIDS cases).

Agency Comments

At the request of the Committee, we did not obtain written comments on this report. However, we discussed it with agency officials and incorporated their comments as appropriate.

As arranged with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies to the Secretary of Health and Human Services, the Director of CDC, and other interested parties, and will provide copies to others on request.

Please call me on (202) 275-6195 if you or your staff have any questions concerning this report. Other major contributors to this report are listed in appendix VI.

Sincerely yours,



Mark V. Nadel
Associate Director, National and
Public Health Issues

Contents

Letter		1
Appendix I		10
CDC's HIV-Prevention Program	Background	10
	Prevention Strategies	12
Appendix II		16
Delivery of Counseling and Testing Services	HIV Counseling and Testing Services Widely Available, but Identification of HIV Infection Slow	16
	Some Counseling Services Are Limited	22
	Services After Posttest Counseling Limited	25
	Effective Outreach Activities Limited	26
Appendix III		29
Monitoring and Evaluation of the Counseling and Testing Program	Slow Progress in Establishing Quarterly Statistical Report Database	29
	KABB Data Surveys Inadequate and, Therefore, Abandoned	31
	Lack of On-Site Program Reviews Impairs Assessment of the HIV Program	33
	Too Early for Results From Funded Evaluations	33
Appendix IV		35
Timeliness of Funding for HIV-Prevention Programs	Overview of Budget Process	35
	Commitment Rate Improving	35
	Personnel and Contractual Problems Main Causes of Uncommitted Funds	38
Appendix V		40
Locations Visited	California	40
	New York	40
	Texas	40
Appendix VI		41
Major Contributors to This Report		

Tables

Table II.1: HIV Tests Done, Posttest Counseling Sessions Provided, and Return Rate by Type of Counseling and Testing Location (1989)	24
Table III.1: KABB Surveys Completed by 61 CDC-Funded Health Departments (Feb. 1989)	32
Table IV.1: Ranking of CDC HIV-Prevention Awards and Health Departments by Percentage of Reported 1989 Uncommitted Funds	37

Figures

Figure II.1: Total HIV Tests Conducted Nationally by Risk Group (1989)	19
Figure IV.1: Trend in Rates of HIV Uncommitted Funds (1986-89)	36

Abbreviations

AIDS	acquired immunodeficiency syndrome
C.A.R.E.	Community AIDS Resources and Education Program
CDC	Centers for Disease Control
CPS	Center for Prevention Services
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HRSA	Health Research Services Administration
IV	intravenous
KABB	knowledge, attitudes, beliefs, and behaviors
NIDA	National Institute on Drug Abuse
NIMH	National Institute of Mental Health
STD	sexually transmitted disease

CDC's HIV-Prevention Program

Background

At-Risk Population for HIV Infection

Acquired immunodeficiency syndrome (AIDS) is emerging as one of the most significant public health problems of this century.¹ At present, no therapy exists to eliminate the human immunodeficiency virus (HIV) or restore an immune system damaged by it. Currently, no vaccine exists to protect susceptible people from infection.

Many more people are HIV infected than have AIDS. CDC estimates that about 1 million Americans are currently HIV infected. Moreover, among adults and adolescents, at least 40,000 new HIV infections occur each year; among newborns, as a result of perinatal HIV transmission, another 1,500 to 2,000 new infections occur each year. These people and infants are at risk of developing AIDS. Meanwhile, those infected can transmit the virus to others.

Transmission has most often occurred during unprotected intimate sexual contact; the sharing of needles and syringes used to inject controlled substances like heroin and cocaine; and pregnancy. Most events that facilitate HIV transmission involve behavior that people have some ability to control. CDC believes that the spread of HIV can be slowed or stopped if people are informed, motivated to act, and encouraged to maintain risk-eliminating behavior changes.

History and Impact of HIV Infection

From 1981, when AIDS was first recognized, through 1990, more than 100,000 people in the United States have died from AIDS. Most deaths from AIDS have occurred among homosexual/bisexual men and among women and heterosexual men who are intravenous (IV) drug users. Although most deaths occurred among whites, death rates per 100,000 population have been significantly higher for blacks and Hispanics.

Of the estimated 1 million persons in the United States infected with HIV, CDC expects about 165,000 to 215,000 will die during 1991-93. The impact of AIDS has been greatest among men 25 to 44 years of age, contributing substantially to the overall increase in deaths among this

¹This appendix is based on the following CDC materials: (1) Guidelines for AIDS Prevention Program Operations, CDC (Oct. 1987); (2) Melinda Moore, M.D., "Counseling, Testing, Referral and Partner Notification: Priorities, Strategies, Issues and Trends," Center for Prevention Services, CDC; (3) Fiscal Year 1989 Annual Report, Division of STD/HIV Prevention, HHS; (4) Justification of Appropriation Estimates for Committee on Appropriations: Fiscal Year 1991, HHS, CDC; and (5) Morbidity and Mortality Weekly Report, Vol. 39, No. RR-16, 1991.

group during the 1980s; in addition, AIDS is becoming a leading cause of death among women. By 1988, AIDS had become the third leading cause of death among men 25 to 44 years of age; on the basis of current trends, it is likely that in the early 1990s, AIDS will rank among the five leading causes of death in women in this same age group.

The impact of AIDS on mortality patterns has been greater in certain areas of the United States—such as Los Angeles, New York City, and San Francisco—than in others. In some locations, such as New York State, AIDS has become the leading cause of death among Hispanic children 1 to 4 years of age and the second leading cause of death among black children of the same age.

In addition to these mortality statistics, measures of the public health impact of HIV infection and AIDS include morbidity, disability, and health care costs. For example, the AIDS epidemic is straining the resources of public hospitals. In addition, in 1989, private insurers paid more than an estimated \$1 billion for reimbursement of AIDS-related claims for life and health insurance, an increase of 71 percent from 1988. The impact of HIV infection and AIDS on mortality in the mid-1990s to the early 2000s will depend on present efforts to prevent and treat HIV infection.²

CDC has lead federal responsibility for HIV control, funding and supporting HIV prevention activities, such as counseling and testing services in state and local health departments and other selected entities;³ education activities in the nation's public school systems; a national media campaign; and epidemiologic studies and disease surveillance for HIV infection.

CDC's HIV programs have grown dramatically and now account for about one-half of CDC's budget, with 1991 funding set at \$495 million. Funding for HIV control in 1990 (\$443 million) was 13 times greater than when the program began in 1985 (\$33 million). CDC allocated about half of its 1990 HIV program funds (about \$217 million) for HIV prevention activities and targeted over one-third of that amount (\$82 million) for counseling programs.

²"Mortality Attributable to HIV Infection—AIDS—United States, 1981-1990, Morbidity and Mortality Weekly Report, Vol. 40, No. 3, 1991, pp. 41-44.

³HIV counseling and testing include education about AIDS and HIV infection, as well as testing (including blood tests to determine a person's antibody status) for HIV infection. In response to HIV infection, the immune system produces antibodies that are detectable through blood tests; antibody status is positive if HIV antibodies are identified in the blood and negative if not.

The Center for Prevention Services (CPS) administers CDC's HIV prevention program, principally through cooperative agreements⁴ with 65 state, local, and territorial health departments. CPS's role includes providing funds, as well as technical assistance, and monitoring health departments' HIV prevention programs to help ensure that funds are effectively used.

Health departments use the CPS-awarded HIV-prevention funds for various approved activities, as well as operation of sites for HIV counseling and testing. These include stand-alone counseling and testing sites (which CDC refers to as "alternate test sites"),⁵ created specifically for HIV testing, as well as counseling and testing services provided within other special purpose programs, such as sexually transmitted disease (STD) clinics, drug treatment facilities, and other locations. In addition to treatment activities unrelated to HIV, these clinics provide HIV testing, pretest and posttest counseling, and partner notification.

The health departments also conduct various health education and risk reduction activities, including (1) street outreach programs for IV drug users, prostitutes, and runaway youth, (2) group counseling of HIV-infected people, and (3) programs to educate health care workers. The health departments also use CDC prevention funds to finance community-based organizations that target outreach activities to minority and other at-risk groups. CDC also directly funds minority and community-based organizations that do outreach.

Prevention Strategies

Since there are no effective therapies or vaccines to cure or prevent HIV infection, information and education continue to be the most viable options available to combat the growing epidemic. CDC is conducting a national program designed to prevent HIV infection among people at increased risk. The program provides financial and technical support to all states and territories—as well as selected cities—for planning, implementing, and evaluating HIV-prevention activities.

⁴A cooperative agreement is a financial mechanism used in lieu of a grant when substantial federal involvement in the recipient's carrying out of the program is anticipated during the funding period.

⁵After the Food and Drug Administration approved an HIV-antibody test for screening blood and plasma donations in March 1985, CDC began funding alternate sites to provide antibody tests, at no cost to those at high risk for AIDS, outside the blood bank setting.

Education Strategies

Preventing the spread of HIV requires an education strategy effective in modifying risk-associated behaviors. This strategy has two main components. The first component is designed to reach high-risk people at a personal level, as individuals. A great many people with risk factors for AIDS misperceive their personal risk or deny that risk in spite of targeted educational campaigns. The focus of program services at the personal level is to provide high-risk individuals with education tailored to each individual's unique situation and particular needs for assistance. Program services also offer specific guidance and arrange referrals to help each high-risk individual eliminate the risk of further transmission. This first component of the strategy is carried out through the (1) CDC-funded Counseling and Testing Program, (2) voluntary counseling and testing that takes place in other settings, and (3) for infected individuals, voluntary referral for counseling and testing of sex partners and needle-sharing partners.

The second component of the AIDS prevention strategy directs pertinent AIDS information to the general public and to selected subgroups of the general public on the basis of specific needs identified for each. It is designed to reach people at a nonpersonal level (for example, as members of various populations, including the general public, through the mass media, written materials, speakers' bureaus or peer group presentations, and educational outreach using street people or former IV drug users) with messages that they must then individually process for personal relevance. Messages aimed at high-risk populations will probably reach many individuals who are receptive to acknowledging their personal risk. CDC initiated the AIDS Health Education/Risk Reduction Program, which was designed in part to carry out this component of the AIDS prevention strategy.

The Counseling and Testing Program

The Counseling and Testing Program attempts to maximize the proportion of people at risk who (1) are offered and receive educational counseling about HIV and the HIV test; (2) accept and receive HIV-antibody testing; (3) return for HIV-antibody test results; (4) are offered and receive post-test counseling; (5) if infected, participate in partner notification; and (6) if infected, are referred for, and receive, further medical and prevention services.

Counseling and testing services were first established in sites other than blood banks in 1985 with the licensure of the HIV-antibody test. These alternate test sites provided wider access to the antibody test at locations other than blood banks, which use the test to screen donated blood

to help protect the blood supply. Since 1985, counseling and testing services have been established at STD, family planning, drug treatment, and other clinics where at-risk people receive health care. The purpose of the counseling and testing services has evolved and expanded to include serving as a gateway to other services, such as drug treatment, STD treatment, and contraceptive services. The services also serve as a point where people at risk can be helped to initiate safer behaviors and as a starting point for partner notification.

Of all HIV-prevention efforts, counseling and testing services receive the highest level of resource support from CDC. The evolution of federal testing policy has followed improvements in efforts to provide prevention and medical services to HIV-infected people. CDC funds for counseling and testing have grown from \$9.8 million in the 1985 program year to \$89.2 million in 1989.

Knowledge of HIV-infection status and appropriate counseling can assist people in initiating changes in behavior that will reduce the risk of infecting others or of becoming infected. Positive behavioral changes can also take place in the large number of people who elect not to be tested, but receive risk-reduction counseling. In addition, early detection of HIV infection, followed by referral, can lead to optimal medical management and partner notification.

In the 1989 HIV-prevention cooperative agreement, approximately \$89.2 million was awarded for state and local counseling and testing services to meet these specific goals:

- to provide education to help initiate behavior change and reduce risky behavior;
- to provide an at-risk individual with knowledge of his or her current HIV status;
- to prevent the spread of HIV infection by providing HIV-infected people with information about behaviors essential for avoiding the transmission of the virus to others;
- to refer infected people to a medical provider capable of providing follow-up care and medical management of HIV-related illnesses;
- to identify sex partners and needle-sharing partners who need to be aware of their risk of HIV infection;
- to provide information, testing, and counseling to identified sex partners and needle-sharing partners; and
- to encourage sex partners and needle-sharing partners to avoid any future behavior that might result in HIV infection.

Among the 63 recipients with cooperative agreements in 1989, the total number of reported counseling and testing sites carrying out these goals was 6,256. One-third of tests have come from alternate test sites set up to provide only counseling and testing services. Another one-third of tests have been done in STD clinics; the remaining third comes from other types of clinics or sites that have also integrated HIV counseling and testing services into their ongoing programs, such as family planning clinics and drug treatment facilities.

Delivery of Counseling and Testing Services

Only a small proportion of those believed to be infected have been identified by the CDC Counseling and Testing Program, even though program services have been widely available. This is because many of those at high risk, particularly IV drug users, have not been tested. Several innovative, effective outreach services have been implemented in some locations, but IV drug users are very difficult to reach. Moreover, regardless of their risk, relatively few of those tested have returned for their test results.

Limited follow-up has been done to convince people to return for their test results. CDC requires counseling and testing locations to refer those found to be HIV infected to long-term counseling and medical care. But this does not ensure that such services will be available in the community or that people will use such services. Little long-term counseling or case management services are available in many communities for HIV-infected people identified by CDC counseling and testing services.

HIV Counseling and Testing Services Widely Available, but Identification of HIV Infection Slow

HIV Counseling and Testing Services

CDC distributed about \$89 million in 1989 through cooperative agreements to 63 state and city health departments,¹ which provided HIV counseling and testing services in 6,256 sites. About one-third of the counseling and testing has taken place in sites set up solely for HIV testing; the remaining two-thirds of services have taken place in sites not set up for HIV testing, such as sexually transmitted disease (STD) clinics.

There are several components to CDC's prevention efforts, listed here in the order in which people generally receive them:

- outreach: (1) to educate at-risk groups about AIDS and behavior modification and (2) to refer them to treatment as well as HIV counseling and testing services;

¹In 1990, CDC increased the number of cooperative agreement recipients to 65.

- pretest counseling at a site: (1) to convince the client to undergo an HIV test by discussing benefits of testing and (2) to educate the client about HIV infection and the ways to prevent its spread;
- HIV testing: to determine if the client is infected;
- posttest counseling: to provide clients with (1) knowledge of their HIV-infection status and (2) education to initiate behavior change to reduce risky behavior and avoid HIV infection for themselves or others (test results are not released unless the client can be counseled); and
- follow-up: if necessary, to convince those clients who have been tested to return for their results and posttest counseling.

In addition, infected clients are referred to medical and counseling services and efforts are made to notify partners (so that these high-risk people also might be counseled and tested).

Although services are received in the above order, we first discuss the results of testing because it identifies those providing the highest risk of infection to others who are themselves most in need of assistance. We focus on HIV drug users, a high-risk group with low participation in counseling and testing services. Next, we discuss counseling, as this is the means by which positive behavioral changes can be initiated, even among the large number of people who elect not to be tested or fail to return for test results. Last, we discuss the outreach components of prevention efforts (funded through prevention funds other than those specifically targeted to counseling and testing).

HIV Tests Identify Small Percentage of Estimated Infections

Less than 20 percent of Americans estimated to be infected with HIV have been identified by CDC-sponsored testing services. Although CDC-funded programs have performed an estimated 3 million HIV-antibody tests since 1985, these tests have identified only about a maximum of 170,000 of the CDC-estimated 1 million HIV-infected people in this country.² One reason for the low yield is that many of those tested are the “worried well,” and are not at high risk.

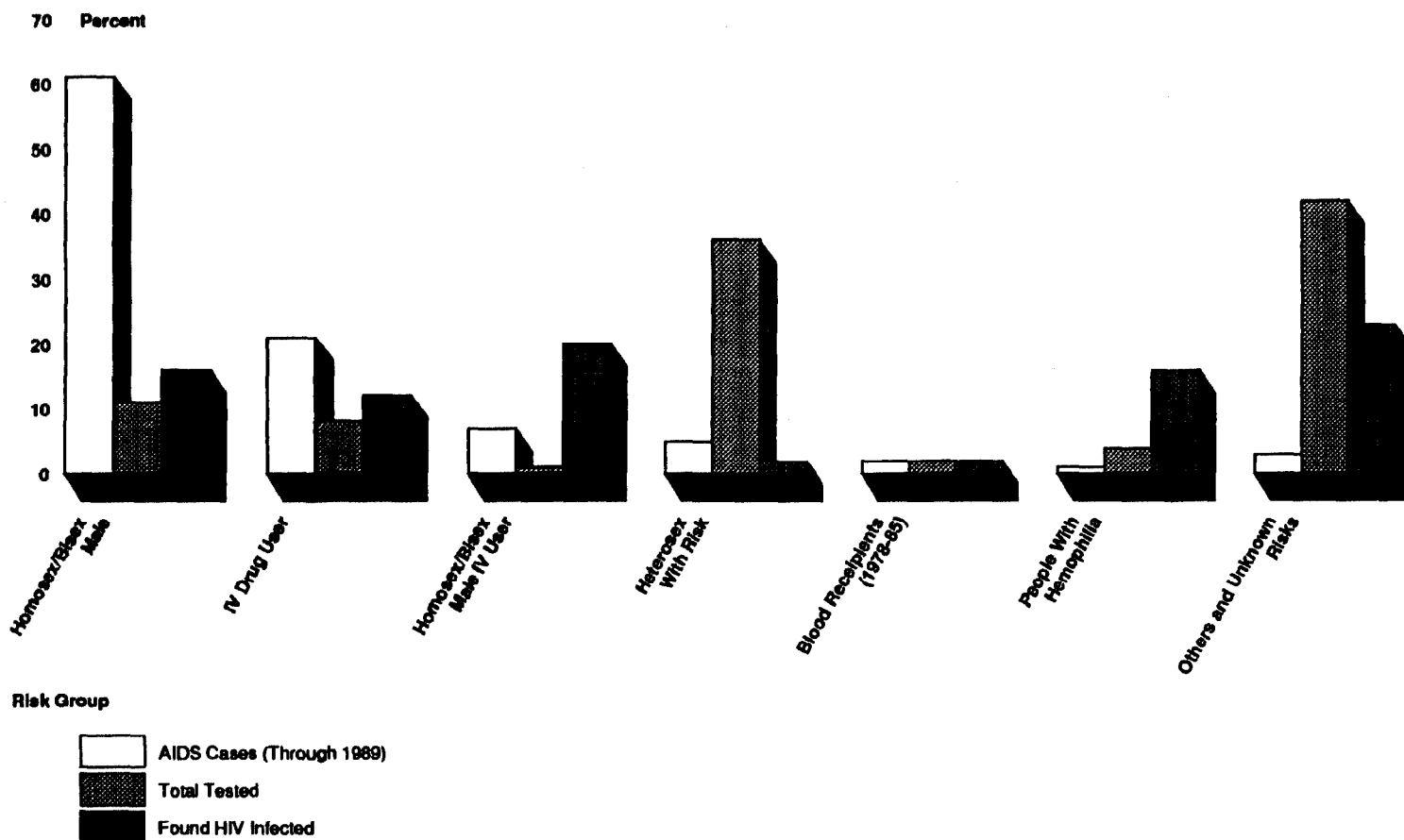
Over 1 million tests were conducted at 6,256 CDC-funded testing sites in 1989 alone, according to program statistics reported to CDC. This represents a 58-percent increase over the tests reported the previous year. We

²What is unknown is how many of these 170,000 tests are retests of the same people. In addition, an unknown number of people have been tested for the HIV antibody in hospitals, outpatient medical facilities, physicians' offices, blood-donation centers, military facilities, and other settings. Some of those tested in these other settings have not been informed of test results and could also have been tested previously.

did not find any direct connection between the increased demand for HIV testing and research results, published in the spring and summer of 1989, that early preventive treatment can delay the onset of AIDS in HIV-infected people. Health officials suggested that the increases probably reflected increased emphasis on counseling and testing, more providers routinely offering such services, better reporting, and public reaction to aggressive education campaigns.

As shown in figure II.1, data reported to CDC by health departments show that most people being tested are not in the highest risk groups. Relatively few (8 percent) identified themselves as high-risk IV drug users. The data show that many not at risk are being tested. However, it is not that the number of such concerned people tested should be reduced, but rather that more of those at high risk need to be reached.

Figure II.1: Total HIV Tests Conducted Nationally by Risk Group (1989)



Source: Centers for Disease Control.

Testing Services for IV Drug Users

Nationally, as of September 1990, the IV drug-user group was second only to the homosexual/bisexual male group in terms of risk for contracting AIDS. In several cities, the number of AIDS cases among IV drug users exceeds that among homosexual men. Yet, in spite of the high risk, relatively few IV drug users receive HIV counseling and testing. In fact, overall, counseling and testing services are more likely to be provided to those at low risk, or unknown risk, than to IV drug users.

Some published statistics show a wide variation in IV drug users' participation in voluntary testing: 85 percent (37 of 46 clients) in a Veterans Administration methadone clinic in Minneapolis; 38 percent (114 of 300) in a methadone clinic in New Bedford, Massachusetts; 24 percent (235 of

970) in a methadone outpatient center in Sacramento, California; 80 percent (365 of 459) in a drug-free treatment facility in Sacramento, California; and 12 percent (37 of 314) in a methadone treatment program in Long Island, New York.

The study at the Long Island methadone treatment program sheds some light on why an individual at risk would choose not to be HIV tested. In that study, researchers found that the IV drug user's perception of counselor interest in his or her taking the test affected the decision. Further, there was some evidence that the AIDS education provided in the pretest counseling discouraged undecided clients from taking the test. Other reasons cited for not taking the test were that the IV drug user (1) had enough problems without more bad news, (2) believed being tested would serve no purpose, (3) feared or was unwilling to learn the outcome, or (4) was concerned about confidentiality.

To focus on the IV drug-user population, CDC's 1989 program announcement required each state and local health department to develop a joint plan with its respective substance abuse agencies; each department was to establish HIV counseling, testing, and partner notification in every public drug treatment facility. To assist the departments, CDC published a model joint plan for HIV-tuberculosis testing in drug treatment facilities. The fiscal year 1990 program announcement expanded the joint plan to include private nonprofit drug treatment facilities. Relatively few publicly funded drug treatment facilities, however, actually offer counseling and testing services on-site to their clients; only 10 to 20 percent of all IV drug users are in treatment at any given time.³

On the basis of CDC data provided by cooperative agreement recipients, as of December 31, 1989, only about 4 percent (267 out of 6,287) of facilities providing drug treatment nationwide were also providing HIV counseling and testing services. As a result, only 20 percent of the 125,488 IV drug users tested in 1988 and 1989 were tested at drug treatment facilities. Consistent with these data, few drug treatment facilities in the states we visited provide HIV counseling and testing services, for example:

- In Texas, of 455 licensed drug treatment facilities, about 115 are publicly funded. HIV counseling and testing services are available in 16 publicly funded programs, including all 7 publicly funded methadone

³The Effectiveness of Drug Abuse Treatment: Implications for Controlling AIDS/HIV Infection, Office of Technology Assessment, September 1990.

maintenance treatment centers. With limited resources, for each of its major cities Texas has focused on providing at least one HIV counseling, testing, and outreach program in every drug treatment facility.

- In New York, about 4 percent (12 of the estimated 322 programs) of the state's drug treatment facilities offered HIV counseling and testing services at multiple sites, with most in New York City. New York concentrated on placing its counseling and testing services in a small number of comprehensive treatment centers located in areas with high incidence of HIV infection and IV drug use rather than introducing HIV counseling and testing services into as many sites as possible.
- In California (including the Los Angeles and San Francisco project areas), counseling and testing are funded in 18 percent (65 of 360) of the publicly funded drug treatment facilities.

Some project areas we visited have undertaken initiatives to make HIV counseling and testing services more accessible to those at high risk. For example, when New York City's Department of Health expanded the number of sites offering anonymous counseling and testing, it purposely located these sites in well-established community health centers in neighborhoods where drug use was endemic. Also in New York City, the Department of Health recently established an "outposted" counselor program to expand HIV counseling and testing services. Under this program, the department hires and trains HIV counselors; it then deploys them to medical settings serving high-risk clients, to whom the counselors provide confidential HIV counseling, testing, and referrals to follow-up care. These settings serve many past and current IV drug users and their partners who have not been counseled and tested. Most of these medical providers do not have the resources to support HIV counseling and testing services in addition to their primary functions.

In Texas, the Dallas County Health Department has been conducting off-site testing by assigning counselors on a part-time basis to several clinics and a community college. In Austin, C.A.R.E. (Community AIDS Resources and Education Program) tries to reach drug users wherever they are by obtaining broad coverage through radio, television, and black or Hispanic newspapers; making presentations at local jails, drug treatment centers, or other places at which drug users might congregate; conducting street outreach activities day and night; and providing transportation to and from the C.A.R.E. facility for those without transportation or reluctant to travel outside their own neighborhoods. In Houston, to make testing more accessible, Over-the-Hill, Inc., a community-based assistance organization, uses a van as a mobile testing site.

Since 1986, CDC has emphasized expanding HIV counseling and testing in STD clinics and other health care settings in neighborhoods where people (such as IV drug users) are typically at high risk of contracting HIV infection. For example, 10 to 15 percent of those at STD clinics, a New York City health official estimated, are IV drug users. Nearly 16 percent of IV drug users tested, Texas officials reported, were tested in STD, family planning, or prenatal clinics.

There is resistance by some drug treatment professionals to establishing testing services if there is no access to other support services. Drug treatment professionals also differ on when, during treatment, HIV counseling and testing would support rather than undermine recovery. Some drug treatment program directors resist locating drug treatment with HIV counseling and testing services. This is because they believe that testing resulting in HIV-positive findings could negatively affect the treatment process by introducing a sense of hopelessness. Severe physical space limitations, officials said, also restrict expansions in any public services.

In addition to barriers to testing set up by some drug treatment professionals, the drug users themselves set barriers because they are resistant to formal systems, are unlikely to keep appointments, and may not know where to go for services.

Some Counseling Services Are Limited

CDC's pretest counseling—aimed at (1) convincing people to undergo HIV testing and (2) educating people about HIV infection and ways to prevent its spread—has been available, but many people choose not to be counseled or tested. There has been limited follow-up by sites providing testing to convince people to return for their test results. After informing people they are HIV infected, CDC requires that counseling and testing sites refer those infected to long-term counseling and medical services; however, this does not ensure that such services will be used by those infected. Moreover, in many communities, long-term counseling or case management services are simply unavailable or, if available, often already functioning at capacity.

CDC officials believe that testing, although it identifies those providing the highest risk of infection to others and most in need of medical and other assistance, is just one element of the Counseling and Testing Program. Counseling is the educational and preventive component of the program and also the means to assist people in coping with HIV infection.

Pretest counseling, in particular, provides information on how to prevent the spread of HIV even to those who refuse to be tested or who do not return for their test results. In this section, we discuss pretest counseling (aimed at educating people and convincing them to be tested), posttest counseling (aimed at delivering information on HIV status, educating people about how to prevent transmission and where to obtain further help if infected, and providing limited emotional support), and follow-up (to convince people to return for their test results).

Pretest Counseling Available, but Many Choose Not to Be Tested

Pretest counseling aimed at providing AIDS education and convincing people to be tested is available to everyone in sites with CDC-funded programs, but not everyone avails themselves of those services. We found that many people (who were pretest-counseled or listened to presentations on HIV infection and testing in clinics) chose not to be tested—unless they visited alternate test sites, set up expressly for counseling and testing. In Los Angeles, for example, of 35,748 people pretest counseled in publicly funded clinics in 1989, only 12,317 were tested. In drug treatment facilities, studies have shown HIV-testing refusal rates ranging from 15 to 88 percent.

The states we visited require a pretest written informed consent from each person; every person who signs this is pretest counseled. Pretest counseling includes a discussion on the nature of the disease and its causes, the benefits of testing, the test procedure, and the meaning of test results.

Posttest Counseling Available, but Often Unused

CDC reported that in 1989, only 39 percent (394,317 of 1,013,904) of all those tested returned for their test results and requisite posttest counseling, as shown in table II.1. Those who were tested at locations other than alternate test sites were considerably less likely to return for their test results. For example, people receiving treatment for an infection may agree to the blood test for HIV detection. However, health officials have learned, once the reason for entering the clinic, such as the treatment for an STD was resolved, people have no motivation to return for their HIV status.

**Appendix II
Delivery of Counseling and Testing Services**

Table II.1: HIV Tests Done, Posttest Counseling Sessions Provided, and Return Rate by Type of Counseling and Testing Location (1989)

Type of location	Tests done	Posttest counseling sessions	Return rate (in percent)
Alternate test sites	372,436	240,629	65
STD clinics	310,430	65,655	21
Drug treatment facilities	21,862	10,610	49
Family planning clinics	71,659	18,349	26
Prenatal obstetrics clinics	43,759	20,775	47
Other health departments	28,173	6,146	22
Prisons	44,347	12,973	29
Colleges	13,326	1,590	12
Private doctors/clinics	43,618	3,642	8
Other	41,178	10,539	26
Unknown	16,921	380	2
Total	1,013,904	394,317	39

Source: Centers for Disease Control.

Posttest counseling generally includes a discussion of the HIV test results, the implications of those results for a person as well as any sex partners or needle-sharing partners, assistance in deciding how to notify these partners, and referrals for medical or counseling services. Any person who returns for test results must be counseled. The information provided and session length differ depending on whether the person is HIV infected or not.

Follow-Up Limited

Follow-up on those not returning for test results is limited. It is generally described as difficult, but in project areas we visited, follow-up became impossible in programs that permit those who come for counseling and testing to remain anonymous. New York State officials pointed out that providers it funded usually have a policy or plan for follow-up, but it is often extremely difficult because of a lack of staffing, the disintegration and violence of client neighborhoods, and homelessness.

In situations where confidential services are provided, such as at STD clinics, the clinics frequently have limited resources and more than enough work without the additional burden of following up on those who have not returned for their test results. Some clinics do remind those tested, by letter or telephone call, to return for their results. A major obstacle, however, to follow-up in sites offering confidentiality is the use of false names and addresses, CDC officials noted.

In CDC's 1990 announcement, program requirements specified, for the first time, that recipients of funds must establish a system for prevention-oriented follow-up of HIV-infected people. This should include counseling, diagnosis and treatment of tuberculosis and STD infections, medical evaluation, admission to drug treatment (when appropriate), and, in the case of women, referral for contraceptive services to minimize the risk of further HIV transmission. Such services might be, for example, counseling partners of infected people, alone or with the infected, to teach and reinforce safe behavior. Although referrals are given, some health officials said, counselors rarely have the time to follow up to ensure that the HIV infected seek out needed services. In some cases, needed services may be unavailable.

Services After Posttest Counseling Limited

The extent of posttest counseling and the availability of long-term counseling for the HIV infected varies widely between and within individual states. Health officials pointed to the need for case management services for the HIV infected, especially among the poor and IV drug users. The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 authorized several programs that would address these needs.

Although CDC views its program responsibilities as ending with posttest counseling because it is not a treatment provider, CDC does require referrals for medical and psychosocial support services for those found HIV positive. The referral by a CDC-funded clinic providing HIV counseling and testing services, however, does not always mean the services needed are available in the community or that they will be used.

In our visits to the various project areas, we heard that long-term counseling and case management services are needed for HIV-infected people.⁴ This is particularly true, New York officials pointed out, for the poor and drug-abusing populations; for them, AIDS is only one of a multitude of basic problems they face on a daily basis: lack of food, shelter, and clothing; unemployment; crime; violence; and a sense of hopelessness.

After the first posttest counseling session, the amount of counseling services provided by publicly funded counseling and testing sites varies considerably. In California, the state only reimburses test sites for one posttest counseling session, held to transmit the test results, and refers

⁴For this study, we defined long-term counseling as providing support services to a person after posttest counseling in order to reinforce the need for behavior modification and to help those testing HIV-positive cope with the infection. Under a case management approach, staff assume an advocacy role for an HIV-infected person and obtain necessary medical or social services for that person.

the person to available follow-up services. At New York City-funded counseling and testing locations, HIV counselors will conduct up to four counseling sessions after the posttest counseling session. For New York State-funded counseling and testing sites, however, only one additional session beyond posttest counseling can be provided because of staffing limitations. In Texas, the C.A.R.E. unit in Austin—a program that provides HIV counseling, testing, and referral services under one roof—will meet with and counsel those tested as long as the services are wanted.

For those with AIDS, we recently reported that mental health and psychiatric services were limited in the five communities we reviewed.⁵ The Health Resources and Services Administration (HRSA), another agency of the Department of Health and Human Services (HHS), reported that available services in many communities for those with AIDS or HIV infected are relatively uncoordinated, fragmented, and expensive. In New York State, state-funded community service projects that provide case management services are overwhelmed with work. Community-based organizations are willing to provide HIV-related services, but, officials noted, these organizations lack the funds. In Texas, the Texas Commission on Alcohol and Drug Abuse pointed out, in its recent 5-year plan, that (1) limited funds are available to treat the medical problems of HIV-infected people and people with AIDS and (2) community resources and services to which HIV-infected people are referred are overextended.

HRSA has sponsored several programs that begin to address the need for long-term counseling and care of HIV-infected people. Through its community health care services for AIDS program, funded, in part, by CDC, HRSA focuses its resources on outpatient services, home health care, and hospice care. HRSA awarded 3-year HIV service demonstration grants to 25 metropolitan areas for (1) coordinating community service providers of case management services and (2) identifying service gaps. The Ryan White Act authorized funding for these types of programs in those metropolitan areas disproportionately affected by the HIV epidemic, but the act was only partially funded. About \$220 million of the original \$875 million was appropriated.

Effective Outreach Activities Limited

Not only are counseling services sometimes limited in reach and scope, but it is often difficult to contact and provide any services to some groups at risk, such as IV drug users. Outreach activities are designed to

⁵AIDS: Delivering and Financing Health Services in Five Communities (GAO/HRD-89-120, Sept. 13, 1989).

target HIV prevention services to these difficult-to-reach groups. CDC funds outreach activities through the Health Education/Risk Reduction and Minority Initiatives components of its cooperative agreements with health departments or by directly funding minority-based and community-based organizations. Outreach activities target such groups as IV drug users, prostitutes, runaway and homeless youth, and other high-risk people not in treatment or not receiving social services. Such activities may take place in correctional facilities, shelters for runaways and the homeless, housing projects, community health centers, mobile vans, churches, or on the streets.

Although we observed some effective outreach activities at the project areas we visited, CDC pointed out that not all outreach activities are effective. CDC officials said that those that have succeeded have done it through hard work, dedication, and strong and lasting working relationships with departments of health, other community-based organizations, treatment programs, and service providers.

Some outreach activities have been effective in pulling people into counseling and testing, as well as support services, in a few of the limited locations at which they have been available. These activities have demonstrated the feasibility of reaching people who have traditionally been difficult to reach.⁶ Research studies are beginning to show that outreach activities can lead to behavioral change. Preliminary results from National Institute on Drug Abuse (NIDA) projects in Chicago, Houston, Miami, Philadelphia, and San Francisco have shown that outreach and intervention activities have led to changes in IV drug use and sexual behavior.⁷

Outreach staff work on the streets not only to provide information on AIDS and HIV, but to encourage behavior modification, entry into drug treatment programs, and to make referrals to HIV counseling and testing. Outreach workers for the California Prostitutes Education Project in San Francisco, for example, speak with prostitutes to provide AIDS education and inform them about the additional AIDS education, counseling, and testing services available in a nearby mobile outreach unit (run as part of a collaborative effort by Project AWARE, Association of Women's AIDS Research and Education). In New York City, outreach workers for the

⁶The Effectiveness of Drug Abuse Treatment: Implications for Controlling AIDS/HIV Infection, Office of Technology Assessment, Sept. 1990.

⁷"Update: Reducing HIV Transmission in Intravenous Drug Users Not in Drug Treatment—United States," Morbidity and Mortality Weekly Report, 1990, Vol. 39, pp. 529-38.

Adolescent AIDS Program Street Outreach Project typically do the following: discuss how HIV is transmitted and how to reduce risk, answer questions, hand out literature and condoms, provide referrals to agencies serving adolescents and the homeless, and provide the AIDS hotline number for information on HIV testing.

In San Francisco, the Mission Neighborhood Health Center operates a mobile HIV education project, and outreach workers encourage HIV testing and offer transportation to testing locations. The Larkin Street Youth Center has a street outreach team that provides high-risk youth with education about substance abuse and AIDS. The team refers youth to the center, which, among other counseling services, provides HIV counseling and testing in its medical clinic. In New York City, for IV drug users in the boroughs of Bronx, Brooklyn, Manhattan, and Queens, the state-funded AIDS Outreach Program does street outreach, education, and referral. Each borough has a team of outreach workers, many of whom are recovered addicts. The outreach workers refer IV drug users to state and city counseling and testing locations, drug treatment programs, and medical and social services; demonstrate how to use bleach to clean needles; and disseminate literature. State personnel also staff a van that provides on-site HIV counseling and testing.

Providing Counseling Services in Languages Other Than English

Although not normally classified as outreach, counseling must be understandable to non-English speakers in order to be useful. CDC program guidance provides that counseling and testing services must be conducted in a culturally sensitive manner and in a language specific to the client. Although neither CDC nor two of the three states we reviewed had any statistics on the number of bilingual HIV counselors or the languages they speak, we found that the language capabilities available at counseling and testing sites generally reflect the character of the neighborhoods in which the sites are located. In the states we reviewed, counseling is generally available in English and Spanish.

Several locations we visited have taken innovative steps to ensure language is not a barrier to HIV counseling and testing. California state guidelines for alternative testing sites, for example, recommend that bilingual and bicultural counselors be hired if 5 percent or more of those using a particular site are non-English speaking. In Los Angeles, a consortium of six Asian/Pacific agencies is staffed by HIV counselors who collectively speak a wide variety of Asian/Pacific languages. In San Francisco, a team of minority counselors, who are bilingual in several languages, rotate between four counseling and testing locations.

Monitoring and Evaluation of the Counseling and Testing Program

Monitoring includes CDC's oversight of the Counseling and Testing Program; evaluation refers to CDC's assessments of the effectiveness of approaches used to change behaviors. After several years' efforts to set up systems for collecting data to monitor counseling and testing activities, CDC has convinced some of its grantees to voluntarily collect the most useful kind of program data—for individual cases—but has not yet been able to create a usable, reliable database from these individual-level data. In addition, CDC has been unable to carry out many formal, on-site program reviews due to staffing constraints.

CDC had required its cooperative agreement recipients to collect data on people's knowledge, attitudes, beliefs, and behaviors (KABB) related to AIDS, but most did not comply, citing the sensitive nature of the questions. A number of state officials feared that the sexual and drug use behaviors covered in the survey would upset many people in their communities. CDC has, consequently, abandoned the survey approach first used and is exploring ways to collect these vital data that would help in planning and evaluating program effectiveness. CDC and other agencies, however, have funded several evaluations of the effectiveness of counseling and testing services, although only preliminary results are available.

As a result of the type of statistics collected, the failure to collect KABB data, and lack of reviews, little detailed information is available on the effectiveness of HIV counseling and testing services, particularly as they relate to changing high-risk behaviors. Final results of the recently funded evaluations will not be available for several years, but preliminary results from some of these studies indicate that street outreach and counseling activities do contribute to reducing high-risk behaviors.

Slow Progress in Establishing Quarterly Statistical Report Database

Counseling and Testing Program data are needed to (1) monitor the program, (2) evaluate the success in reaching targeted groups, such as IV drug users, and (3) plan further efforts to attain program goals. Since July 1988, CDC has required that recipients funded under cooperative agreements submit quarterly aggregate statistical reports; these should detail the numbers of counseling sessions, tests, and positive test results by type of testing location, risk category, and demographic characteristics. Most of these recipients have complied.

Recently, CDC developed a computer form by which each location can record data on each person who arrives for services and send these data directly to CDC. CDC and funding recipients can then perform much more

sophisticated analyses using these data. These analyses in turn permit better fine-tuning of program efforts. Two data collection systems currently in use are aggregate-level monitoring and individual-level monitoring.

Aggregate-Level Monitoring Data

The usual way statistical monitoring data are currently collected is in quarterly aggregate-level data on older, manual report forms. In 1989, of the 63 health departments receiving funds, 52 (83 percent) provided all the mandatory quarterly reports. In 1990, CDC restricted funding in 15 project areas because of reporting deficiencies in these quarterly summary reports.

Individual-Level Monitoring Data

The new voluntary, scannable individual-level reporting system (1) permits considerably more flexibility in data analysis than the older aggregate-level reporting system and (2) provides the means to monitor and more thoroughly evaluate characteristics and testing behavior of those seen at individual counseling and testing locations.

At a recent CDC-sponsored workshop, CDC noted that unlike the summary data, individual-level data can be analyzed to establish program priorities for certain types of sites or certain people. Additionally, individual-level data can be used to strengthen programs by identifying locations and corresponding demographic data where operational problems are indicated. Such indicators could include test refusals or high rates of those tested not returning for test results. A further advantage of individual-level data is that the data can also be summarized to provide the required quarterly summary reports. CDC is further modifying the scannable system to allow it to track other program indicators, such as how many HIV-infected people come to a test site and how many are offered counseling and testing.

The individual-level reporting system has considerable merit, both because of the level of detail and the automation involved. However, there are two problems with the resulting database: (1) such data are voluntarily submitted by only 40 percent (25) of funding recipients and (2) we found discrepancies in the numbers reported to us by individual states when compared with the CDC numbers retrieved from the database for those states. Before placing confidence in analyses from this system, CDC must increase its use by grantees and address problems in the reliability of the data collected. We reported, in 1989, that CDC officials had said it would take 2 years to develop a sufficient database.

But we pointed out then that these data were needed as soon as possible to set objectives and evaluate basic program outcomes.¹

Limitations of Both Types of Monitoring Data

Two main limitations in arriving at conclusions on the number of people infected apply to both the aggregate-level monitoring and individual-level monitoring systems. First, duplicative tests on the same person cannot be eliminated from the total counts. Consequently, all numbers referring to people tested are overstated because of retesting. This could have major ramifications because, in the states we reviewed, health department guidelines recommend that those testing HIV negative should be retested if their behavior places them at risk or their test results were indeterminate. In fact, considerable retesting is done now, a San Francisco official said, in alternate test sites. On the basis of data from four publicly funded HIV prevention programs that have monitored repeat tests, CDC reported an estimated 12 to 30 percent of HIV-antibody tests (representing 3 to 18 percent of positive test results) were done on those previously tested.

Second, both systems only cover publicly funded counseling and testing services. But even among these, gaps in reporting exist. In Texas, for example, neither system reports services provided for purposes of medically managed care by the publicly funded Texas Department of Mental Health and Mental Retardation or the Texas Youth Commission.

KABB Data Surveys Inadequate and, Therefore, Abandoned

Over the last 4 years, CDC's attempts to gain information from a required survey on KABB relevant to AIDS have been unsuccessful. Health departments (recipients of CDC funds) have not done the survey because of reported resistance and fear of resistance from respondents or the local community, even though CDC has required the survey since 1986. Finding the survey more complex and costly than originally envisioned, CDC is no longer requiring the KABB survey and is currently working on a replacement.

Few health departments have completed KABB surveys targeted at high risk groups—CDC's main concern. Although CCD required health departments to conduct such surveys each year, relatively few—only about 30 percent—completed them; in table III.1, the number completed, by risk group, is shown.

¹AIDS Education: Issues Affecting Counseling and Testing Programs (GAO/HRD-89-39, Feb. 3, 1989).

**Appendix III
Monitoring and Evaluation of the Counseling
and Testing Program**

**Table III.1: KABB Surveys Completed by
61 CDC-Funded Health Departments
(Feb. 1989)**

Risk groups	Health departments completing KABB surveys	
	Number	Percent
Homosexual/bisexual men	33	54
IV drug users	18	30
Health care workers	18	30
Minority populations	16	26
Women of reproductive age	9	15

Note: CDC data were only available on 61 of the 65 funded programs.

Additionally, CDC officials discovered, of those KABB surveys that were completed, most provided little useful information due to methodological problems. But KABB data are critical to managing and monitoring state and local HIV-prevention programs. They provide a base that program officials can use to identify (1) gaps in HIV knowledge and (2) the extent to which behaviors that spread HIV are practiced. A health department could then use this survey information to establish priorities and objectives for its HIV program. CDC could also use this information to (1) monitor health departments' distribution of funding and (2) help develop HIV program information to identify effective program activities.

CDC officials realized that the KABB monitoring strategy was more complex and costly than they originally envisioned. To provide useful information, these surveys must be properly planned, include appropriate sampling techniques, and be conducted with scientific precision. Both CDC and state officials, however, have acknowledged that the health departments generally did not have qualified staff to properly conduct these complicated surveys. Furthermore, health departments did not generally hire behavioral scientists to help conduct such surveys.

In fiscal year 1990, CDC provided KABB survey funding to far fewer health departments than in previous years (only 7 versus 61 in the previous year). CDC is exploring alternative approaches, such as interviews, for gathering such KABB data.

Lack of On-Site Program Reviews Impairs Assessment of the HIV Program

Citing staff shortages as a key problem, CPS has conducted few program reviews of health departments' HIV-prevention services. Formal on-site reviews, one of CDC's key monitoring tools, provide independent information to measure progress toward program objectives. These program reviews provide an in-depth assessment of an individual recipient's efforts. CDC historically has conducted about 10 program reviews annually for its STD control program. From 1986 to 1989, however, CDC conducted only 2 reviews of health department HIV-prevention programs; additionally, no more than 5 reviews will be completed in 1990 although CDC had planned to conduct 10 to 15. Without such reviews, (1) CDC is hampered in using its nationwide experience to improve local HIV programs and (2) timely identification and correction of problems will not be made.

Staffing shortages have been the primary factor limiting CDC's ability to conduct program reviews. To closely review program activities, these reviews include about five CDC staff visiting a health department for about 1 week. We reported in 1989 that staff shortages had prevented such reviews.² In February 1990, CDC advertised four positions for review team staff. CDC had initial difficulty, however, finding and hiring qualified staff for these positions. As a result, CDC used its direct hire authority to fill these four positions, and staff began work in early October.

Despite staff shortages, the director of CPS said, the center has put priority on working with health departments in order to get a broad range of HIV-prevention services to people. As a result, little time has remained for formal monitoring efforts. The center does review and improve HIV-prevention services through other, less documentable monitoring efforts, such as routine phone conversations with program staff, although more monitoring is needed.

Too Early for Results From Funded Evaluations

Nearly all federally sponsored research studies of HIV counseling and testing effectiveness have yet to be completed; only a few have published preliminary results. CDC is funding several of these efforts. (NIDA and the National Institute of Mental Health [NIMH] are also conducting research on the response of IV drug user and other high-risk groups to different HIV counseling and outreach activities.) Therefore, the relative

²AIDS Education: Staffing and Funding Problems Impair Progress (GAO/HRD-89-124, July 28, 1989).

effectiveness of various settings, strategies, and methods in providing HIV counseling and testing is not yet known.

We previously stated that the federal government should take the lead in conducting studies of what does and does not work in HIV education.³ We need to know how to motivate long-term changes in the sexual and drug-using behaviors that spread HIV. Since last we reviewed CDC's prevention efforts 2 years ago,⁴ some progress has been made.

CDC's efforts to evaluate HIV counseling and testing began during 1990. Meanwhile, CDC has been preparing a paper for publication that will summarize over 40 studies worldwide, addressing various aspects of counseling and testing related to behavioral change. Initially scheduled for publication in June 1990, this paper is expected in 1991. CDC is also working with a contractor to assess CDC-funded counseling, testing, referral, and partner notification services in five cities.

CDC is also funding three studies that will compare the effect of enhanced counseling with standard counseling in drug treatment facilities and STD clinics. A study of four locations (drug treatment facilities) in Connecticut and Massachusetts started later than expected; the study began to enroll participants and collect data in July 1990 and is scheduled to be completed in 1992. Separate studies will also be conducted in STD clinics in Houston and San Antonio, Texas. These studies are in the planning stages and will not begin enrolling participants until 1991.

Since September 1987, NIDA has funded 41 community demonstration projects to study and change the high-risk behaviors of both IV drug users and their sexual partners. Two of these projects have been completed, and the rest will be completed by July 1991. After the projects end, NIDA will continue to fund the research portion of the projects, but not the service delivery portion. NIMH is also (1) funding several longitudinal studies designed to evaluate different ways of counseling the HIV infected and (2) identifying changes in risk behaviors.

³Issues Concerning CDC's AIDS Education Programs (GAO/T-HRD-88-18, June 8, 1988).

⁴AIDS Education: Issues Affecting Counseling and Testing Programs (GAO/HRD-89-39, Feb. 1989); AIDS Education: Staffing and Funding Problems Impair Progress (GAO/HRD-89-124, July 1989); AIDS Education: Activities Aimed at the General Public Implemented Slowly (GAO/HRD-89-21, Dec. 1989); and Issues Concerning CDC's AIDS Education Programs (GAO/T-HRD-88-18, June 8, 1988).

Timeliness of Funding for HIV-Prevention Programs

Health departments are now doing a better job of committing funds for HIV-prevention programs than when the programs began. Personnel and contractual problems, however, have continued to cause some delays in committing funds.

Overview of Budget Process

Each year, CPS provides funds to state and local health departments. Health departments do not have to pay out these funds in the budget year awarded, but, according to their agreement with CPS, they should commit the funds within the budget year.

Committing funds involves transactions—such as placing orders, awarding contracts, or hiring staff—that require payment during the current or future budget periods. If a staff position is unfilled when planned, the unspent salary amount is recorded as uncommitted. Likewise, if an approved contract is not awarded in the budget year, the contract amount is recorded as uncommitted. Generally, a health department's uncommitted funds are carried over by CDC for use in the next year. Uncommitted funds are of concern because they represent delayed HIV services, which had been planned for in the budget year.

Normally, about 10 to 15 percent of all CPS program funds remain uncommitted at year's end, stated CPS officials. For example, CPS's STD program is a smaller grant program; its operation is similar to that of the HIV program, except that the HIV program includes more contracting. The 1989 STD program's uncommitted funds were 21 percent of the total awarded for that program. In a second example, CPS also provides immunization grants to health departments. Of the 1989 immunization program's awarded funds, 13 percent of the total was uncommitted.

Commitment Rate Improving

HIV uncommitted fund rates for counseling and testing services decreased from 33 percent in 1987 to 18 percent in 1989 (see fig. IV.1).

**Appendix IV
Timeliness of Funding for
HIV-Prevention Programs**

**Figure IV.1: Trend in Rates of HIV
Uncommitted Funds (1986-89)**



Note: For 1986, only health education and risk reduction cooperative agreement information was available.

Those areas with the greatest AIDS crisis had some of the highest uncommitted balances, as well as a higher average uncommitted balance, than other areas. Of the 15 state health departments with the highest AIDS caseloads, 8 had uncommitted balances of 22 percent or more in 1989. Details of each health department's 1989 uncommitted balance are shown in table IV.1.

**Appendix IV
Timeliness of Funding for
HIV-Prevention Programs**

Table IV.1: Ranking of CDC HIV-Prevention Awards and Health Departments by Percentage of Reported 1989 Uncommitted Funds

State health departments with highest AIDS caseloads	Award amount	Uncommitted funds	
		Amount	Percent of award
Puerto Rico	2,130,442	1,077,038	51
Illinois	6,171,925	2,599,413	42
Washington, D.C.	5,264,025	1,478,709	28
California	10,915,280	2,805,626	26
Massachusetts	6,488,462	1,551,841	24
Ohio	4,645,791	1,114,599	24
New York State	21,431,844	4,627,871	22
Washington	3,448,806	762,590	22
New Jersey	9,972,837	1,866,354	19
Texas	8,767,138	1,295,452	15
Louisiana	3,898,033	566,731	15
Florida	12,882,051	1,993,828	15
Georgia	5,445,708	714,653	13
Pennsylvania	6,546,010	655,473	10
Maryland	7,669,643	242,500	3
Subtotal	115,677,995	23,352,678	20
All other health departments			
Kentucky	768,498	352,764	46
New York City	15,383,623	4,719,667	31
West Virginia	1,287,362	368,767	29
South Dakota	399,831	108,063	27
Colorado	3,958,277	892,908	23
Wyoming	448,765	98,804	22
Virginia	3,589,744	765,382	21
Kansas	562,137	113,280	20
Indiana	2,085,214	382,719	18
Tennessee	2,462,782	376,973	15
North Mariana	126,489	19,217	15
Houston	2,943,109	441,979	15
Los Angeles	9,298,266	1,367,115	15
Mississippi	1,057,905	149,631	14
Delaware	1,130,000	153,651	14
Connecticut	4,257,291	578,177	14
Nebraska	637,151	86,297	14
New Mexico	1,804,406	233,338	13
New Hampshire	747,545	96,127	13
Utah	1,114,788	140,275	13

(continued)

**Appendix IV
Timeliness of Funding for
HIV-Prevention Programs**

State health departments with highest AIDS caseloads	Award amount	Uncommitted funds	
		Amount	Percent of award
Oregon	2,236,759	269,095	12
Maine	670,684	75,237	11
American Samoa	91,167	9,874	11
North Carolina	2,615,265	282,984	11
Guam	171,079	18,475	11
Arizona	2,334,480	246,935	11
Wisconsin	2,143,476	200,000	9
Iowa	1,115,147	99,016	9
Rhode Island	1,028,854	77,809	8
South Carolina	2,287,175	169,503	7
Arkansas	1,434,856	84,683	6
Michigan	5,375,521	269,421	5
Marshall Islands	102,087	4,212	4
Nevada	667,936	14,000	2
Minnesota	2,590,648	47,873	2
Oklahoma	1,666,448	24,155	1
Montana	614,432	8,613	1
Palau	52,711	690	1
Idaho	498,596	431	0
Hawaii	1,639,018	0	0
Alaska	945,906	0	0
North Dakota	520,192	0	0
Vermont	530,873	0	0
Alabama	1,978,132	0	0
Missouri	3,264,952	0	0
San Francisco ^a	a	a	a
Micronesia	a	a	a
Virgin Islands	a	a	a
Subtotal	90,639,577	13,348,140	15
Total	206,317,572	36,700,818	18

^aFinancial status report not received by CDC as of September 19, 1990.

**Personnel and
Contractual Problems
Main Causes of
Uncommitted Funds**

The percentage of uncommitted funds at year-end has decreased, CDC officials said, because (1) HIV funding increases have slowed overall, (2) vacant staff positions are being filled, (3) HIV-contracting systems have matured with many contracts now in continuation phases, and (4) added attention to this problem has provided an increased sense of urgency to committing funds. We found the main causes of uncommitted funds to be personnel and contractual problems.

Personnel problems, such as hiring freezes or a lack of qualified applicants, resulted in positions for HIV programs being unfilled as planned. For example, in January 1989, the District of Columbia health department had funds for 76 staff positions. Of the 76 positions, 31 (41 percent) were unfilled by December 31, 1989. The primary difficulty, District of Columbia officials said, was finding qualified personnel. In Massachusetts, a statewide hiring freeze in 1989 delayed hiring. About 36 percent of approved HIV positions were vacant for 6 months or more, basically as a result of the freeze.

Contractual delays also resulted in uncommitted funds. Public Health Service regulations require health departments to provide specific data before CDC approves contract proposals. This information includes (1) a description of services to be performed, (2) an itemized budget, and (3) method of contractor selection. If a health department does not provide such data, CDC withholds the contract funds. By the time a health department can provide needed data and CDC releases the funds, it may be too late for the health department to commit the funds through the contract award within the budget year. In 1989, such was the case with over one-half of the New York health department's contractual uncommitted funds.

Accounting methods also tended to overstate the actual amount of uncommitted funds. State fiscal officials listed as uncommitted some funds that actually were committed, but unspent, at the end of the budget year. For example, the Ohio fiscal department classified committed funds, unspent by the end of the budget year, as uncommitted funds. This accounted for virtually all of the Ohio health department's 1989 contractual "uncommitted funds."

Locations Visited

California

AIDS Health Project, San Francisco
Asian Pacific AIDS Education Project, Los Angeles
Bayview-Hunter's Point Foundation, San Francisco
California Department of Health Services
California Prostitutes Education Project, San Francisco
County of Los Angeles Department of Health Services
Department of Health and Human Services, Long Beach
El Centro Human Services Corporation, Los Angeles
Gay and Lesbian Community Services Center, Los Angeles
Larkin Street Youth Center, San Francisco
Mission Neighborhood Health Center, San Francisco
San Francisco AIDS Foundation
San Francisco Department of Public Health
San Francisco General Hospital
YES Project, San Francisco

New York

Addiction Research and Treatment Corporation, Brooklyn
Adolescent AIDS Program Street Outreach Project, New York
Anonymous Counseling and Testing Site (ACT VII), East Harlem
Chelsea STD Clinic, New York
Daytop Village, Inc., New York
New York City Department of Health
New York State Department of Health
New York State Division of Substance Abuse Services
St. Luke's-Roosevelt Hospital Center, New York

Texas

AIDS Arms Network, Dallas
C.A.R.E. Program, Austin
Dallas County Health Department
Dallas Urban League, Dallas
Ethel Daniels Foundation, Inc., Dallas
Frio Street Project, San Antonio
Houston Department of Health and Human Services
Montrose Clinic, Houston
Over-the-Hill, Inc., Houston
Texas Commission on Alcohol and Drug Abuse
Texas Department of Health
Texas Department of Mental Health and Mental Retardation

Major Contributors to This Report

Human Resources Division, Washington, D.C.

Janet Shikles, Director, Health Financing and Policy Issues,
(202) 275-5451
Michael Gutowski, Assistant Director
Cheryl J. Oros, Assignment Manager
Laurel Rabin, Reports Analyst

Atlanta Regional Office

Don Riffe, Regional Management Representative
Martin Landry, Evaluator-in-Charge
Magdalene Harris, Site Senior
Kathy R. Alexander, Evaluator

Boston Regional Office

Donald B. Hunter, Evaluator-in-Charge
Linda W. Dunbrack, Site Senior
Elizabeth Q. Nacar, Evaluator



**United States
General Accounting Office
Washington, D.C. 20548**

**Official Business
Penalty for Private Use \$300**

**First-Class Mail
Postage & Fees Paid
GAO
Permit No. G100**

Ordering Information

The first five copies of each GAO report are free. Additional copies are \$2 each. Orders should be sent to the following address, accompanied by a check or money order made out to the Superintendent of Documents, when necessary. Orders for 100 or more copies to be mailed to a single address are discounted 25 percent.

U.S. General Accounting Office
P.O. Box 6015
Gaithersburg, MD 20877

Orders may also be placed by calling (202) 275-6241.