
HIV INFECTION AMONG STREET YOUTH



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The purpose of this inspection is to determine the scope and nature of the problem of HIV infection among street youth. It provides an overview of the various issues presented by the epidemic, an understanding of how those issues are being addressed, and a set of recommendations for future action. The report was prepared under the direction of Mark R. Yessian, Ph.D., Regional Inspector General of Region I, Office of Evaluation and Inspections, and Martha B. Kvaal, Deputy Regional Inspector General. Participating in this project were the following people:

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HIV INFECTION AMONG STREET YOUTH

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EXECUTIVE SUMMARY

PURPOSE

The purpose of this inspection is to determine the scope and nature of the problem of HIV infection among street youth and of the services that address the problem.

BACKGROUND

AIDS is a major threat to adolescents. Although very few cases of AIDS have been reported among teenagers, the number of reported cases among 20- to 29-year-olds with AIDS suggests a high level of HIV infection (which causes AIDS) among teenagers. Some adolescents seem to be in more danger than others. They are "street youth," who have diverged from society's mainstream and have fallen through the safety net. Understanding the impact and future threat of HIV among street youth is critical for two reasons. First, existing public health strategies for preventing and treating HIV infection were initially developed for adult gay men and may have limited utility for this population of young people whose lifestyles suggest more specialized approaches. Second, recent medical developments indicate that the use of AIDS therapies can delay the onset of symptoms among people infected with the virus. This makes early identification of infected street youth crucial for improving their chances of longer-term survival.

FINDINGS

Both the risk and current rate of HIV infection are almost certainly higher among street youth than among adolescents in general.

Thousands of young people have been infected and street youth are in particular danger. While the infection rate for all adolescents nationwide appears to be less than one percent, for some subpopulations of adolescents the rate may be as high as seventy percent. High infection rates among street youth are a predictable consequence of the risky behaviors that constitute their lifestyle. The most common risk behavior for street youth appears to be unprotected sexual intercourse, which in some cases involves sex in exchange for basic survival needs.

Special needs of street youth compromise HIV prevention, testing, and treatment efforts.

Prevention: Basic survival needs of street youth overwhelm education efforts aimed at reducing high-risk behavior. The preventive measures which have proven successful in adult populations may be ineffective in this population.

Testing: Youth workers often hesitate to test street youth for HIV because of the lack of proper counseling and available follow-up services.

Treatment: Traditional medical institutions and street youth don't mix. Street youth are unlikely to seek out traditional institutions for care, in part because many such facilities actively reject them.

The fight against HIV among street youth suffers from gaps in research on behavior change models, seroprevalence, and treatment protocols.

Behavior change models: Researchers and providers lack both basic information on street youths' sexual behavior and models for curtailing unsafe sex and drug use.

Seroprevalence: No one knows for sure how many street youth are infected. Because of insufficient data, attention and money may not be invested where they are most needed.

Treatment protocols: Manifestation of HIV disease in adolescents is an understudied phenomenon. One factor hindering progress in this area is the dearth of adolescents enrolled in clinical trials of HIV-related therapies.

At the local level, categorical requirements and fragmented program structures weaken service delivery for street youth with or at risk of HIV infection.

Even when a range of services is offered, categorical requirements and other access barriers frequently render those services inaccessible to street youth. These requirements include money, consent, and age ranges. In addition, fragmentation of funding sources and different ideological approaches impose serious barriers to service delivery.

At the Federal level, the overall response to the problem of HIV infection among street youth is inadequately focused and coordinated.

The breach in coordination has especially severe ramifications for efforts involving HIV and street youth, because of the large number of Federal agencies with responsibility for AIDS, adolescents, or both. In comparison to other groups affected by the disease, street youth seem to attract little attention from the Department, the public, traditional youth advocates, and Congress.

RECOMMENDATIONS

The Public Health Service

The Public Health Service (PHS), through the Centers for Disease Control (CDC), should conduct additional seroprevalence research to measure the scope of the epidemic among street youth.

The PHS should collect baseline data on the sexual behavior patterns of street youth.

The PHS, through the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) and the CDC, should conduct research on behavior change strategies designed to reduce the risk of HIV infection among street youth.

The PHS should conduct research on the natural history and manifestation of HIV infection in adolescents and develop appropriate counseling, testing and clinical protocols for treating youth who are infected.

The Public Health Service and the Office of Human Development Services

The PHS, in collaboration with the Office of Human Development Services (OHDS), should design and implement a strategy to curb HIV infection among street youth in six cities with large populations of street youth and high rates of HIV infection.

COMMENTS

We received comments on the draft report from the Public Health Service (PHS), the Office of Human Development Services (OHDS), and the Assistant Secretary for Planning and Evaluation (ASPE) within the Department. These comments reflect general concurrence with our findings and recommendations. Based on the comments we received from PHS and OHDS, we altered our final three recommendations. We included the Centers for Disease Control (CDC) among the PHS components which should conduct behavioral research among street youth, and broadened the scope of our recommendation concerning the manifestation of HIV disease among adolescents. We also changed the final recommendation to make it more consistent with a pending CDC initiative aimed at preventing HIV infection among street youth in six cities. The PHS, rather than OHDS, is now recommended as lead agency for the six-city strategy. The detailed comments and our responses to them appear in appendix A.

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INTRODUCTION

PURPOSE

The purpose of this inspection is to determine the scope and nature of the problem of HIV infection among street youth and of the services that address the problem.

BACKGROUND

Acquired immunodeficiency syndrome (AIDS) is a major threat to adolescents. Although only 604 people aged 13-19 have been diagnosed with AIDS¹, this figure drastically understates the level of human immunodeficiency virus (HIV) infection, which causes AIDS. The median incubation period for HIV appears to be about 10 years, and may be longer for adolescents than for adults.² This means that only those teenagers who were infected very young or who progressed from infection to AIDS very quickly are included in those 604 cases. Most people infected as teenagers will not develop AIDS before adulthood.

The number of AIDS cases reported in young adults provides a more accurate picture of the HIV epidemic among adolescents. Since 1981, 31,176 cases of AIDS have been diagnosed among 20- to 29-year-olds.³ This group, many of whom must have been infected as teenagers, represents 20.1 percent of all AIDS cases reported to the CDC since the epidemic began. More than 26 percent of all 13- to 29-year-olds who have developed AIDS were diagnosed in the last year.

Some adolescents seem to be at higher risk than others. These youth are the ones who have become displaced from society's mainstream and have fallen through the safety net. They are referred to as "disconnected," "disenfranchised," or "marginalized." Generally out of home, out of school, and out of work, they spend their days looking for food, shelter, recreation, and money on our urban streets. They revolve through our system of juvenile courts and jails, mental health facilities, foster care homes, and runaway shelters. We refer to this group as "street youth."

Street youth lead troubled lives. Data from runaway and homeless shelters indicate high rates among this population of physical and sexual abuse, emotional disturbance including depression and suicide attempts, and illegal drug use.⁴ These problems can be either the cause or the result of life on the streets.

Our definitional boundaries of street youth are intentionally fluid. Strict age limits are undesirable because, unlike adolescents in stable residential and educational environments, street youth are likely to have peers, sexual contacts, and needle sharing partners who are older than the traditional cutoff ages of 18 or 21.

Definitions based on behaviors are equally problematic because of the variety of living arrangements and life histories among this population. For example, only a small percentage of street youth visit runaway shelters. A definition based on such visits would bar from consideration other youth in equally unfortunate situations and at equal risk for HIV infection. For purposes of this report, therefore, "street youth" refers to those adolescents and young adults who find their primary support systems and social structures on city streets rather than at home or in school.

The lack of firm inclusion criteria makes estimating the size of the street youth population difficult. However, all people who meet the Federal definition of homeless youth, and many who meet the Federal definition of runaway youth, could be considered street youth.⁵ Estimates of the number of youth permanently on the streets fall between 100,000 and 300,000, with as many as 1,000,000 to 2,000,000 running away from home each year.⁶

Understanding the impact and future threat of HIV among street youth is critical for two reasons. First, existing public health strategies for preventing and treating HIV infection were initially developed for adult gay men and may have limited utility for this population of young people whose lifestyles suggest more specialized approaches. Second, recent medical developments indicate that use of AIDS therapies can delay the onset of symptoms among people infected with the virus. This makes early identification of infected street youth crucial for improving their chances of longer-term survival.

Several operating divisions of the Department of Health and Human Services (DHHS) oversee activities relating to HIV and adolescents. The list includes the Office of Human Development Services (OHDS) and virtually every component of the Public Health Service (PHS): the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); the Centers for Disease Control (CDC); the Health Resources and Services Administration (HRSA); the Indian Health Service (IHS); the National Institutes of Health (NIH); and the Office of Assistant Secretary for Health (OASH). All of these agencies except NIH and IHS target street youth specifically.

For instance, the National Institute of Mental Health (NIMH), within ADAMHA, is funding research on the prevention and epidemiology of HIV among street youth. The OHDS offers technical and financial assistance to local agencies providing services to street youth through the Runaway and Homeless Youth Program and the Transitional Living Program. A more detailed description of Federal activities relating to HIV and street youth is contained in a separate report: "HIV Infection Among Street Youth: Department of Health and Human Services Programs and Resources," (OEI-01-90-00501).

METHODOLOGY

The methodology for this study is based on literature searches and interviews. The interviews consisted of: (1) formal telephone discussions with representatives of 13 national and 2 local organizations working on issues related to either adolescents or HIV; (2) formal telephone discussions with staff from 20 providers of health care and social services to street youth, representing the two providers serving the most street youth in each DHHS region of the country; (3) site visits to 3 additional service providers; (4) formal telephone and in-person discussions with 15 DHHS officials involved in adolescent or HIV-related research or programming; and (5) supplemental discussions with several researchers, doctors, and government officials. In addition, we requested and received written information from several components of DHHS documenting their efforts relating to HIV and street youth. A more complete explanation of the methodology is contained in appendix B.

FINDINGS

BOTH THE RISK AND CURRENT RATE OF HIV INFECTION ARE ALMOST CERTAINLY HIGHER AMONG STREET YOUTH THAN AMONG ADOLESCENTS IN GENERAL.

Thousands of young people have been infected and street youth are in particular danger.

Data on seroprevalence (the prevalence of HIV infection in a given population) among some groups of youth are collected by three Federal agencies: the Centers for Disease Control (CDC), the Department of Defense (DoD), and the Job Corps, all of which conduct HIV antibody testing.⁷ The CDC's best estimate is that 74,550 young people between the ages of 13 and 24 are currently infected, including those with AIDS. This is a rate of 1.8/1,000.⁸ The rate varies fourfold between demographic groups, from 0.8/1,000 for females both 13-18 and 19-24 to 4.1/1,000 for 19- to 24-year-old males.

Results from other studies and from DoD and Job Corps samples suggest that seroprevalence varies greatly according to geographic and demographic boundaries, with poor urban youth hit hardest by HIV.⁹ Defense Department statistics show that black and Hispanic males have become infected at far higher rates than military recruits in general.¹⁰ The Job Corps data show that HIV is spreading most rapidly in a few metropolitan areas.¹¹ Additional data from CDC reveal that specific, high-risk populations of urban youth face future devastation unless a cure for HIV disease is found in time.¹²

In our own survey of direct providers of services to street youth, we asked for estimates of seroprevalence among the client groups served. Three of the organizations surveyed conduct their own testing and track infection rates as a formal part of their program. The first is a youth shelter in a large southern city. Its clients are being tested anonymously, and are testing positive at a rate near 30/1,000. The second is another nonclinical program located on the west coast which tests only those clients who request it. Staff of this program report an infection rate of 110/1,000. The third is a clinical program that serves and tests high-risk youth referred by other service providers in a large east coast city. Over the past year, 30 of the 95 youth referred to the program have tested positive: a rate of 315/1,000.

High infection rates among street youth are a predictable consequence of the risky behaviors that constitute their lifestyle.

That many adolescents have already been infected with HIV should not come as a great shock. Teenagers often become sexually active and begin experimenting with

drugs and alcohol before they have developed the skills necessary to moderate such behavior. Over 60 percent of young Americans have sex before their 19th birthday. High rates of pregnancy and sexually transmitted diseases (STDs) indicate that most teen intercourse is unprotected.¹³

The behaviors that put street youth at risk for HIV infection are no different from behaviors that are risky for other adolescents, but are probably more frequent and occur in a different and riskier environment. Eighteen of the 23 service providers responding to our survey cited unprotected sex as the behavior most likely to place their clients at risk. Frequently mentioned contributing factors included sex with multiple partners, prostitution, and non-IV substance abuse.¹⁴ In general, providers believe that high-risk sexual behavior is much more common among their clients than IV drug use. On average, respondents reported that slightly less than 8 percent of their clients engage in IV drug use. In contrast, 34 percent consistently engage in "survival sex," *i.e.*, sex in exchange for a broad range of items, including shelter, food, clothing, money, or drugs.¹⁵

In addition to behavior-related risks, physiological factors may further endanger adolescents. Researchers have noted that sexually active adolescents have higher rates of some STDs than do sexually active adults, suggesting that an adolescent's immunologic response to certain viruses may be weaker than that of an adult. One question under consideration by physicians is whether the factors that put adolescents at higher risk for STDs also affects their resistance to HIV infection.¹⁶

SPECIAL NEEDS OF STREET YOUTH COMPROMISE HIV PREVENTION, TESTING, AND TREATMENT EFFORTS.

Prevention: Basic survival needs of street youth overwhelm education efforts aimed at reducing high-risk behavior.

Education has long been used as a primary public health prevention strategy. In the context of HIV prevention, education efforts seem to have led to pronounced changes in behavior among adult gay men.¹⁷ Among street youth, however, there is compelling evidence that education by itself is inadequate as a prevention technique.

Nearly all providers we spoke with reported remarkably high levels of knowledge among their clients about how to avoid HIV infection. Most have conducted tests of their clients' HIV knowledge before and after educational interventions. Estimates of the proportion of clients who now know which behaviors are risky ranged as high as 100 percent. Ten of 23 providers reported knowledge rates of 90 percent or higher, with an overall average of 81 percent. Nevertheless, providers consistently reported that knowledge has little effect on behavior. As described above,

unprotected sex with multiple partners remains a common practice among street youth.

The reasons for this dissonance are complex and probably apply to most adolescents. But in the case of street youth, barriers to behavior change are even more profound and intractable. Providers reported that the need for food, shelter, or drugs displaces knowledge and fear of HIV risks. As one provider stated, "It [HIV prevention] all flies out the window when they don't have a place to sleep." As mentioned above, many street youth exchange sex for shelter or money, and we heard anecdotal evidence from providers in several cities that their clients receive more money for sex without condoms.

Without exception, the providers we talked with identified the shortage of accessible survival necessities -- such as housing, food, and drug treatment -- as a major impediment to successful prevention efforts. Only 2 of 23 providers surveyed believed that existing drug detoxification and rehabilitation services are adequate to meet clients' needs. Research and advocacy organizations concurred with the providers' assessments, stressing the need for basic social support services.

In the absence of an adequate supply of such basic services, most of these providers rely on prevention techniques that are not recognized as particularly effective, even by those who employ them. Although all providers use pamphlets or other written materials and nearly all use educational videos, not one rated either of these methods as particularly effective for changing behavior or preventing infection.

Beyond the barriers to changing a street youth's behavior through education is another factor that is less frequently recognized but highly relevant to HIV prevention among this population: that of general health status and its relationship to transmission. Researchers believe that HIV proliferates when the immune system is active; consequently, a young person who is ill before she comes in contact with the virus may be more likely to become infected.¹⁸ Malnutrition and use of drugs (including alcohol and tobacco) also compromise general health status,¹⁹ and there is conclusive evidence that lesions associated with some STDs heighten the risk of transmission.

Health and mental health problems among street youth result from a number of factors, including poor nutrition and hygiene, as well as limited access to preventive and primary health care services. The relatively poor health status of most street youth has been well documented in a study conducted under the auspices of the Health Care for the Homeless project. The project's findings indicated that the street youth studied were twice as likely to suffer from a chronic disease than a control group of youth who were not homeless. Further, the percentage of homeless girls with STDs was over three times that of their non-homeless counterparts.²⁰ This

suggests that the same behavior may place a street youth at significantly greater risk of HIV infection than her healthy counterpart who is living at home.

Testing: Youth workers often hesitate to test street youth for HIV because of the lack of proper counseling and available follow-up services.

Recent findings²¹ about the ability of zidovudine (formerly AZT) to prolong the life of infected but asymptomatic persons have important implications for street youth. In order for youth to receive such therapy, however, their serostatus (*i.e.*, whether or not they have been infected) must be determined through testing.

Despite recognition of the potential value of early identification and treatment of infected youth, national organizations and service providers are highly ambivalent about the issue of testing. The source of this ambivalence is the inability of current testing sites to deal with the special needs of street youth. Five respondents from research and advocacy organizations expressed serious doubts about HIV testing because they questioned the resources available at or through test sites for youth who learn they are infected. Direct providers communicated the same concern: 13 of 18 responding felt that existing test facilities are not equipped to deal with youth.

By definition, street youth are without traditional social support networks that would facilitate access to counseling and other social services. Ideally, such services should be linked to the testing process, particularly when an infection is confirmed. In the absence of such support, a street youth may learn of his infection at a time when he has no place to sleep, no connection with family, and no immediate prospects for getting off the street. The counseling that accompanies HIV testing, therefore, must be tailored to recognize such circumstances.

Some providers reported suicidal ideation and actual suicide attempts to be common among street youth who learn that they are seropositive. There is some evidence that even youth who attend school and presumably have stronger support systems associate suicide with a positive HIV antibody test.²² One provider we interviewed has documented the incidence of this behavior among its clients who are seropositive. Over a two-year period, 89 percent of these youth have either attempted suicide or engaged in unusual suicidal ideation. Although the link between positive test results and suicidal behavior is still being studied, anecdotal evidence such as this makes understandable the reluctance of some youth workers to recommend HIV testing for street youth.

This is not to say that providers unanimously oppose testing. Most either provide some testing services themselves or refer clients for testing at another site. Nevertheless, every provider in this category reported that the decision to test is made on a case-by-case basis. A number mentioned the availability of medical and

social services for an HIV-positive youth as a primary factor in determining the suitability of testing.

Treatment: Traditional medical institutions and street youth don't mix.

The neglect and abuse suffered by street youth can make them distrustful and reluctant to engage in treatment. One researcher describes the difficulties homeless youth face in gaining access to services as follows: "Emotional problems and drug abuse problems, often in combination, exacerbate the difficulties of engaging and assisting them. They may be openly rejecting of services, particularly those that are not easily accessible to them. Thus, they are easy to disregard and ignore. . . ."23

Street youth are unlikely to seek out traditional institutions for care, particularly because many such facilities actively reject them, considering them poor risks and too difficult to manage.²⁴ The direct service providers we surveyed, most of whom work exclusively with street youth, deal with distrust and alienation by employing extensive outreach programs. Eighteen of 23 reported using outreach workers to locate and engage street youth in services. But clinical care programs, many of which are hospital-based, are less likely to deploy resources for street workers to find infected street youth and engage them in care. Many may not have the resources to conduct active follow-up with youth who do not keep appointments or have difficulty adhering to a prescribed treatment regimen. Every outreach worker we interviewed described the problem of youth's alienation from institutional health care as critical in the overall HIV effort.

THE FIGHT AGAINST HIV AMONG STREET YOUTH SUFFERS FROM GAPS IN RESEARCH ON BEHAVIOR CHANGE MODELS, SEROPREVALENCE, AND TREATMENT PROTOCOLS.

Behavior change models: Researchers and providers lack both basic information on street youths' sexual behavior and models for curtailing unsafe sex and drug use.

Gaps exist in two areas of behavioral research. The first is purely descriptive. Although a number of studies have been conducted to assess the nature and frequency of youths' sexual behavior, many experts agree that there is limited knowledge about how teenagers decide to begin having sex and about the effects of family, school, and peer group experiences on sexual behavior.²⁵ Given the lack of data on the sexual behavior of adolescents in general, it is not surprising that little is known about factors affecting the sexual behavior of street youth in particular. Information about these factors could add significantly to the design of prevention programs aimed at modifying behaviors that place street youth at risk of HIV infection. The National Institute of Child Health and Human Development (NICHD) has prepared the "Survey on Health and AIDS Risk Prevalence" to gather

this kind of information about sexual behavior in the general population. But this survey will not yield information directly applicable to street youth. The data gathered from a survey of this kind directed specifically at street youth could provide some of the baseline information necessary for the design of effective prevention programs for that population.

Research has also been sparse in the more general area of developing and evaluating the effectiveness of HIV prevention strategies for youth.²⁶ There is considerable debate among researchers and practitioners about the relative merits of various behavior change strategies in the context of HIV prevention among adolescents. Some evidence suggests that prevention programs in other health areas such as smoking and teenage pregnancy hold promise for adaptation to HIV prevention.²⁷ There is conflicting evidence about the effectiveness of peer-based education strategies. While some practitioners have found peer education to be popular with youth and useful in transferring information, others believe that peers lose their credibility once they are perceived as counselors.

There is no simple strategy for transferring to younger adolescents behavior change strategies that were effective with adult gay men. The need for modifying behaviors was strongly reinforced among older men by familiarity with peers who were sick and dying of AIDS. But because few infected youth show any symptoms, most street youth are unfamiliar with the shocking and visible signs of AIDS.

Seroprevalence: Because of insufficient data, attention and money may not be invested where they are most needed.

Because of the lag between infection and onset of symptoms, the President's Commission on the Human Immunodeficiency Virus Epidemic recommended in 1988 that researchers focus on HIV infection rates rather than AIDS case reports to measure the progress of the epidemic.²⁸ To date, no national, statistically reliable seroprevalence survey of street youth has been conducted. In fact, it is unclear whether such a survey is possible, given the relatively low number of subjects and their potential unwillingness to participate in such a study. The lack of accurate seroprevalence data, however, may have immediate and negative consequences for street youth in some cities and the organizations serving them.

A new CDC initiative, proposed for Fiscal Year 1991, provides an illustration of the problems facing program designers caused by lack of seroprevalence data. The Division of Adolescent and School Health, within CDC, requested \$5.2 million dollars to fund as many as six city health departments for the purpose of establishing HIV prevention programs for out-of-school youth. To be eligible, cities must have reported at least 2,900 AIDS cases to the CDC by December 31, 1989. The eight qualifying cities are Chicago, Houston, Los Angeles, Miami, New York, Newark, San Francisco, and Washington, D.C.

But the number of total AIDS cases, as discussed above, may be a poor indicator of HIV prevalence, especially among street youth. By relying solely on total AIDS cases, CDC may be missing some cities with equally high rates or large numbers of cases of HIV infection among street youth in comparison to the eight cities just mentioned. For example, the list of eight cities with the highest current infection rates among Job Corps applicants does not include Newark, Houston, Los Angeles or Chicago. Instead, Atlanta, Birmingham, Cleveland, and Baltimore are among the top eight. Alternatively, if *raw numbers* of infected Job Corps candidates are considered, the list of eight cities hit hardest by the epidemic includes Norfolk, Philadelphia, and St. Louis. Samples from the Job Corps applicant population, while not a perfect substitute, almost certainly give a better indication of the problem among street youth than total AIDS cases.

There are probably a number of reasons for the lack of reliable seroprevalence data on youth. In the course of our study we heard several possible explanations, including: 1) because of the small number of AIDS cases among adolescents during the early years of the epidemic, this group was not considered to be at risk; 2) the transient and secretive nature of this population makes them difficult to reach through traditional epidemiologic methods; 3) geographic and ethnographic differences among subpopulations of street youth make extrapolation and generalization to the population as a whole highly speculative; and 4) researchers and clinicians were concerned about the ethics of testing this population for a fatal and stigmatized disease in the absence of medical interventions and social support mechanisms.

An obvious use for additional seroprevalence data is resource allocation. In the coming years, budget constraints will likely force public and private managers to direct money and staff to very specific areas and people. AIDS case reports are of very limited utility in this regard, because they only reflect what was occurring a decade ago. On the other hand, HIV antibody status yields immediate information on the spread of the epidemic.

Treatment protocols: Manifestation of HIV disease in adolescents is an understudied phenomenon.

Complicating the problem of getting youth into medical care are unanswered questions about appropriate clinical protocols for treating youth. Each clinical provider we interviewed expressed concern about the dearth of knowledge regarding physiologic and pharmacologic aspects of treating HIV-infected youth. With the exception of adolescent hemophiliacs, adolescents have not been the subjects of systematic study in such areas as immune response, length of the HIV latency period, disease progression, or response to pharmacologic treatment.

As an example, until 1989 there were no adolescents from 13 to 17 years of age enrolled in the national clinical trials program.²⁹ By October 1989, only 47 adolescents who were seropositive had been enrolled in trial protocols of zidovudine and other HIV-related therapies, and most were male hemophiliacs.³⁰ Weak representation of adolescents among clinical trial subjects can have important consequences: data collected during the trial process are used to determine appropriate dosage levels and schedules for subpopulations of patients. Since gender and age-specific factors can affect dosage, effectiveness, and toxicity of drug therapy, more information about the pharmacodynamics (what drugs do to the body) and pharmacokinetics (what the body does to drugs) of various therapies as applied to adolescents could enhance the quality of available treatment.

Questions about disease progression and illness rate among infected adolescents also have critical implications for providing high-quality care. As one clinician who has recently begun treating HIV-positive youth in a clinic-based program told us, "I need to know more about which AIDS-related illnesses are likely to strike my patients and how those illnesses will manifest themselves in younger people. For example, are my patients likely to suffer from dementia, and if so, what will dementia look like in a teenager and how best can I treat it?" The need for more extensive scientific inquiries about the natural history of AIDS among young people has been described by other clinicians and experts as "crucial in order to address, in a timely and comprehensive manner, the unique problems confronting adolescents with or at risk of HIV/AIDS."³¹

AT THE LOCAL LEVEL, CATEGORICAL REQUIREMENTS AND FRAGMENTED PROGRAM STRUCTURES WEAKEN SERVICE DELIVERY FOR STREET YOUTH WITH OR AT RISK OF HIV INFECTION.

Even when a range of services is offered, categorical requirements and other access barriers frequently render those services inaccessible to street youth.

Even the services that are offered to street youth on paper may be inaccessible in practice. Twenty of the 23 direct service providers in our survey reported significant barriers for their clients in accessing existing clinical and social services. The most frequently cited barrier (mentioned by 15 providers) is lack of ability to pay for needed services.

Not only do street youth lack money to pay for services, but they are frequently denied eligibility for Medicaid because they do not have Social Security Numbers or birth certificates and other required documentation. Sometimes the time and patience required to obtain the documentation and fill out forms and paperwork is

simply beyond the capabilities of adolescents weary or afraid of dealing with the system.

Beyond the cost of care are other barriers, many of which are more complex than the payment issue. During each of our site visits, providers and health officials alike described a number of serious access barriers to programs that would otherwise appear to meet some of the special needs of street youth. The following are examples:

- o *Consent Requirements:* Limitations on the rights of minors to consent to their own treatment can create formidable obstacles to care. The laws, regulations, and court decisions that govern consent are highly complex. There is little consistency among States: some permit minors to enroll themselves in mental health and drug rehabilitation programs, while others require parental consent. Virtually every State allows minors access to certain services associated with STD treatment but some insist on complicated and time-consuming legal procedures beforehand.³²

- o *Age Limits:* By our definition, street youth may range in age from early teens up to about 24 years old. After age 18, however, youths become ineligible for a number of critical services. For example, under the Department's Runaway and Homeless Youth Program, funds given to shelters may not be used to provide services to youths over age 18. Older street youth may be referred to adult shelters that are "wet" (*i.e.*, residents are currently using alcohol and other addictive substances). These shelters house a subpopulation of homeless people very unlike the youths' peer group. In many such cases, sleeping on the street is a more desirable option. Age may also serve as a barrier to drug therapy for youth who are already infected. One project we visited was funded to provide zidovudine treatment only for seropositive youth age 18 or younger.

- o *Length of Stay Limits:* Many programs funded to house street youth limit clients to 15- or 30-day stays. Designed to serve as temporary placements for emergency use, these shelters are increasingly faced with youth who have nowhere to go after this time has elapsed since for many street youth homelessness is not a temporary problem. Program managers from across the country expressed frustration with the absence of longer-term shelter programs. One project in Los Angeles has had a success rate of over 70 percent (measured by the proportion of youths who do not return to street life and are able to support themselves) but only among youth who were offered structured shelter care for at least seven months.³³

- o *Other Conditions of Participation:* Other requirements imposed in some programs may effectively exclude homeless youth from enrollment. At one site we visited, program staff reported the case of a highly motivated young girl who applied for admission to a residential drug program well-known for its high rate of success.

After clearing a morass of legal consent hurdles, they learned that the drug program's family-system approach requires that parents, spouses, siblings or "significant others" take an active part in the treatment process, both for immediate support purposes and continuity of care after discharge. Unfortunately, the young girl's family members were completely disengaged from her, and her peers (who might otherwise have served as significant others) were other homeless youth who were struggling with their own life problems. Requirements like this one may have a sound clinical base, but may also result in exclusion of patients who are not part of traditional family settings.

Fragmentation of funding sources and different ideological approaches impose serious barriers to service delivery.

Given the broad and diverse range of problems that street youth have, the need for service coordination and collaboration among caregivers cannot be overstated. Yet during every site visit interview we conducted, the issue of service fragmentation was identified as a serious problem. To some degree, fragmentation is the result of separate funding streams and program designs, many of which are managed by DHHS. But poor coordination at the Federal level appears to be only one of a range of factors that splinter service delivery for street youth.

In some respects, the particular circumstances of service fragmentation are unique to the locality in which services are delivered. For example, because of their city's geography, providers in Los Angeles must deal with imposing transportation problems when attempting to design and coordinate a treatment plan for a street youth. Distance alone can serve as a serious barrier to a patient's compliance as well as to collaboration among care givers. But there do appear to be some factors that promote fragmentation no matter where the programs are located:

o *Separate Funding From a Variety of Sources:* Many providers expressed frustration with the classification of youth into categories such as "runaway," "prostitute," or "drug abuser." This results from funding programs designed to address discrete problems as opposed to the interrelated needs of individuals. Exacerbating the difficulty is that sources of these "problem funds" are at different public and private levels. The following example, provided by a senior local public health official, may serve to illustrate the potential outcome of fragmented funding streams: Data gathered by the local public health department showed a significant increase in IV drug use in a certain sector of the city. At the same time, seroprevalence rates in that neighborhood began to increase, according to public hospital and clinic data. In separate actions, three different organizations (one drug treatment program, one youth service agency, and one community-based health clinic) applied for and received three separate grants from a Federal agency, a private foundation, and a State agency. All three applied for and received a major portion of overall funding

designated for outreach workers. In the health official's words, "we had outreach workers tripping all over each other out there. In fact, we probably had more outreach workers on the streets than clients when all three programs were in full operation. At the same time, we went begging for outreach work in other parts of the city."

o *Competition Among Providers for the Same Funding:* In some cities that have been particularly hard hit by the epidemic, competition among providers for funding can be fierce. Many small, community-based agencies believe they are out-gunned by larger, more traditional institutions and consequently find themselves in even more intense competition with one another for a relatively small piece of the funding pie. This is not to say that such rivalries preclude any cooperation, but they clearly do not promote the kind of teamwork among providers necessary to maximize available resources.

o *Different Ideological Approaches:* Philosophical differences among providers can also be an impediment to coordinated care. The most frequently mentioned example of this phenomenon was in the area of drug treatment. Many drug rehabilitation programs are premised on a 12-step model that other service providers believe has limited relevance for homeless youth who are addicted to non-IV drugs. Providers told us that "even the language they [drug rehabilitation staff] use is foreign" to other social service workers.

Similarly, there are differences among service providers about the relative emphasis that should be given to case management and to collocation as methods of integrating the delivery of services to street youth. Through the case management approach, street youth in need of services are paired with youth workers who can help guide them through "the system." Many of those working in this field have viewed case management as a core service that is vital to any sustained effort directed to street youth. Indeed, it has become a centerpiece of many demonstration and other project grants concerning street youth.

Yet other service providers, including many we met with, note that case management for street youth is frequently duplicated. They also note that it can be ineffective unless the case managers physically accompany their clients to appointments -- a practice that can put a severe strain on the supply of time and money. These providers suggest greater emphasis be placed on collocating HIV counseling, primary preventive medical care, and other key services under one roof. This approach, they emphasize, would minimize transportation problems and reduce the occurrence of missed appointments. However, it would require a considerable capital investment and could itself lead to some unnecessary duplication of services.

AT THE FEDERAL LEVEL, THE OVERALL RESPONSE TO THE PROBLEM OF HIV INFECTION AMONG STREET YOUTH IS INADEQUATELY FOCUSED AND COORDINATED.

The breach in coordination has especially severe ramifications for efforts involving HIV and street youth.

Coordination within DHHS is particularly important as far as HIV and street youth are concerned. The responsibility for virtually every piece of the fight against HIV is perceived to be shared by more than one Departmental agency. We asked Department officials to identify which part of the Department, if any, should have responsibility for nine separate functions related to combating HIV among street youth. For all but one function, at least 5 of the 14 respondents identified more than one agency.³⁴ Nine thought that "determining what behaviors most commonly lead to the spread of HIV among the street youth population" should be a shared duty.³⁵ Eight thought that more than one agency should "design and evaluate programs to promote behavior change among street youth."³⁶ The only function that seems to lie clearly within a single agency's domain is "determining how many street youth are infected, and where they are." Twelve of the fourteen Department officials responding thought that this was CDC's responsibility. Still, five of the respondents named another agency instead of or in addition to CDC.

The National AIDS Program Office (NAPO) is supposed to "serve as the Public Health Service focus in coordinating and integrating efforts to prevent and control the occurrence and spread of HIV infection and AIDS."³⁷ Its ability to perform that duty may be hampered, however, by several circumstances. First, Departmental bodies which are not part of the PHS have little or no representation at NAPO-organized meetings. For instance OHDS, which sponsors several programs for street youth, does not have an official member on the PHS HIV Leadership Group, the PHS Executive Task Force on AIDS, the Panel on Women, Adolescents, and Children with HIV Infection and AIDS, or the Federal Coordinating Committee on the HIV Epidemic. Its absence from the last group is particularly surprising, because the Federal Coordinating Committee goes beyond the PHS to include such agencies as the Environmental Protection Agency and the National Aeronautics and Space Administration.

Another limit to NAPO's effectiveness may be its emphasis on coordinating PHS programs that are directed at people with access to traditional educational and medical systems. One former NAPO employee told us that HIV-related activities aimed at street youth might be better coordinated through a body focused on the homeless rather than on the disease. Finally, NAPO's mandate appears to be limited to organizing meetings and "networking." It has no control over resource allocation or grant specifications. The decisions on particular programs and policies are ultimately left to the individual PHS components.

The exclusion of OHDS from the PHS coordinating process may explain the 1990 announcement of the Drug Abuse Prevention Program for Runaway and Homeless Youth.³⁸ This program is sponsored by OHDS's Family and Youth Service Bureau. The announcement acknowledges the link between substance abuse prevention and HIV prevention. But the only Federal agencies listed as sources of information on HIV and runaway youth are the National Institute on Drug Abuse (NIDA) and the Office of Substance Abuse Prevention (OSAP). Applicants for this program could clearly also benefit from contact with NIMH, HRSA, and CDC.

Another example of a coordination gap is the existence of two Federally funded curricula on HIV prevention for high-risk youth. In 1987, NIDA's Community Research Branch contracted with Westover Consultants to produce and distribute the AIDS High Risk Adolescent Prevention curriculum. Also in 1987, CDC's Division of Adolescent and School Health awarded money to the National Network of Runaway and Youth Services to develop the "Safe Choices Guide: HIV and AIDS Policies and Prevention Programs for High-Risk Youth." Both are aimed at youth service organizations, some of which are funded directly by OHDS, and include basic educational information and suggestions for promoting safe behavior. We did not investigate thoroughly how or why both projects were funded simultaneously. There may be valid reasons for having two similar curricula, such as comparing their relative effectiveness. But it appears that they were not originally designed to complement each other, and on the surface there is no apparent need for both.³⁹

The above discussion aside, there are parts of the Department that seem to be making progress in fighting the epidemic among street youth. For instance, national advocacy and research organizations applaud the Centers for Disease Control's concern for street youth and other adolescents at high risk of HIV infection. The CDC was the agency most often cited by these organizations as doing particularly well in this area. Both the Center for Prevention Services (CPS) and the Center for Chronic Disease Prevention and Health Promotion (CCDPHP) have been supporting HIV prevention efforts specifically targeted to out-of-school youth. In August 1989, CDC held an internal meeting to identify the most crucial components of HIV prevention programs for out-of-school youth. In October 1989, the Deputy Director for HIV of CPS served as moderator to a PHS Bi-Regional Consensus Conference on HIV and runaway and homeless youth. The resulting recommendations from both gatherings addressed all the key issues raised in this report, including the need for provision of basic services to street youth and for coalition building between local service providers. Although the General Accounting Office recently stated that "CDC has accomplished relatively little in providing HIV education to out-of-school youth,"⁴⁰ CDC appears to have the knowledge, experience, contacts, and commitment to promote effective HIV prevention programs for street youth in the future.

Street youth at risk of HIV infection seem to attract comparatively little attention from the Department, the public, traditional youth advocates, and Congress.

Of the many groups who have been hit hard by HIV, street youth seem to have been the focus of relatively little publicity and political action. Concerted attempts to influence public policy on HIV-related issues remain largely the work of the adult gay community. Public compassion for people with AIDS seems to be directed mainly to those who are considered "innocent," such as newborns and recipients of infected blood products. For example, the only teenager with AIDS who has received national attention and sympathy was Ryan White, a hemophiliac who died in April 1990. As one Federal official told us, street youth have "fallen through the cracks. . . . The heartstrings go out to the young children -- not to the 13- or 14-year-old involved in prostitution."

Street youth may lack sufficiently strong voices in Washington. Two of the most well-known and respected advocacy groups for children's issues did not participate in the survey we conducted for this report. One referred us instead to a publication of theirs that was outdated and contained little information directly relevant to street youth. The other was willing to participate, but felt that they could add little in terms of opinions or insight beyond what was contained in their existing publications. Again, these publications were clearly focused on younger children in traditional settings, and had little to say with regard to street youth. Furthermore, congressional interest in this population appears limited. The only committee to have held hearings on the matter of HIV and street youth recently is the Senate Committee on Governmental Affairs, whose mandate to investigate these issues is indirect at best.

The general absence of focus on street youth may help to explain the Department's comparatively minimal response to the HIV epidemic in that population. When we asked our survey respondents to rate the overall response of the Federal government to the epidemic among adolescents, the ratings they offered were consistently lower in relation to street youth than to youth in general. This was reflected in the responses of direct service providers, national organizations, and even HHS officials.⁴¹

In sum, street youth are easily invisible as a group, have no natural advocacy group, and do not generate the concern directed to other populations most at risk of HIV infection. It should not be surprising, therefore, that they have not become a primary focus of Federal policy makers' attention in the overall HIV effort.

RECOMMENDATIONS

THE PUBLIC HEALTH SERVICE

The Public Health Service, through the Centers for Disease Control, should conduct additional seroprevalence research to measure the scope of the epidemic among street youth.

In order to allocate resources efficiently, policy makers and program managers must have a clearer picture of where and to what extent street youth are becoming infected. Another reason to collect seroprevalence data is to demonstrate the severity of the problem. The long HIV incubation period means there will probably never be a comparatively large number of teenagers diagnosed with AIDS no matter how many teens become infected with the virus. Many teens who become infected will not develop AIDS until they become adults.

Given the difficulties in generating valid national data on seroprevalence among street youth, it seems more appropriate to focus on locality-based data. Collecting such data is necessary if scarce resources for prevention and treatment are to be apportioned effectively. Because infection rates are likely to differ significantly between and perhaps even within metropolitan areas, a large number of sites must be selected for study.

In collecting and analyzing seroprevalence data on street youth, CDC should make full use of reliable data collected from other sources, both public and private. The CDC should make all data easily available to researchers and service providers. This data should be as detailed as possible without jeopardizing individual privacy rights.

The Public Health Service should collect baseline data on the sexual behavior patterns of street youth.

In response to the call by researchers and practitioners for more and better information on factors that encourage high-risk sexual behavior among street youth, the PHS should move quickly to collect this information. The data should be gathered from several metropolitan areas with large concentrations of street youth.

The Public Health Service, through the Alcohol, Drug Abuse, and Mental Health Administration and the Centers for Disease Control, should conduct research on behavior change strategies designed to reduce the risk of HIV infection among street youth.

In the absence of a vaccine, only behavior change will slow or stop the spread of HIV. As mentioned previously, interventions developed for smoking cessation and pregnancy prevention may hold promise for HIV prevention efforts, but there has been little systematic evaluation of such efforts. In the meantime, resources have been channeled to traditional education-as-prevention efforts that clearly have limited utility for street youth. Therefore, behavior change among street youth in particular should be a high priority for additional research efforts. What works for adolescents in general should not be presumed to work for street youth, because the physical demands and psychological effects of street life inhibit the success of traditional HIV risk reduction interventions.

The PHS's research agenda should include modification strategies for all behaviors that place adolescents at risk, including substance abuse as well as high-risk sexual activity. It should continue the search for more effective treatment technologies for users of current drugs of choice such as "crack" cocaine. Because several ADAMHA components (including NIMH, NIDA, OSAP, and the Office of Treatment Improvement) and the CDC have expertise in these areas, PHS should coordinate research initiatives through its Panel on Women, Adolescents, and Children with HIV Infection and AIDS.

The Public Health Service should conduct research on the natural history and manifestation of HIV infection in adolescents and develop appropriate counseling, testing and clinical protocols for treating youth who are infected.

Use of zidovudine and other therapies to delay the onset of symptoms among those infected with HIV represents a major breakthrough in treatment of the disease. But the use of these therapies for young people may be inhibited by a lack of information on the progress of the disease and the effects of such treatments on adolescents. The PHS should therefore further expand its current research efforts in both areas. Disease progression among adolescents should be studied more thoroughly and young people, especially young women, should be represented more broadly in the clinical trials of therapies designed to treat the disease. Data from trials can then be used to guide practitioners in developing treatment protocols and determining appropriate dosage levels, dosage schedules, and treatment of adverse reactions.

THE PUBLIC HEALTH SERVICE AND THE OFFICE OF HUMAN DEVELOPMENT SERVICES

The Public Health Service, in collaboration with the Office of Human Development Services, should design and implement a strategy to curb HIV infection among street youth in six cities with large populations of street youth and high rates of HIV infection.

Local-level service fragmentation and access problems discussed in this report cannot be resolved completely by Departmental efforts. But a combination of technical assistance, financial support, and removal of categorical barriers at the Federal level would create an environment in which service delivery reforms could be made.

We believe that a strategy of focusing on a small number of large urban centers with high HIV infection rates is warranted for three major reasons. One is that by concentrating on specific localities, the particular types of services and service linkages needed can more readily be identified and implemented. A second is that by directing an intensified effort at cities with large populations of street youth and high rates of HIV infection, the Department can have a sizeable impact on the national problem. And finally, by carefully evaluating the effort, the Department and others can gain insights on how to respond more efficiently and effectively to the needs of street youth throughout the country.

As noted earlier in this report, the CDC is already planning an initiative for FY 1991 geared to preventing HIV infection among street youth and other youth at high risk. The PHS is therefore the most logical agency within the Department to assume lead responsibility for implementation of this recommendation. Nevertheless, the PHS should not rely on the CDC initiative to fulfill the recommendation. The PHS should also ensure that the CDC initiative is planned and carried out in collaboration with OHDS because of that agency's direct programmatic responsibility for the street youth population, and with other components of the PHS.

A number of researchers, practitioners, and non-profit organizations have done extensive, and in some cases, exemplary work in examining implementation problems and testing reform models. Staff of the Robert Wood Johnson Foundation as well as participants in the West Coast Scientific Symposium on Health Care of Runaway and Street Youth are two examples. Therefore, we strongly urge PHS and OHDS to ensure that experts from organizations like these participate formally in the planning and development of the six-city strategy.

The HIV prevention strategy should encourage local initiatives; facilitate the provision of basic services that address the survival necessities of street youth; make use of existing Federal programs such as the Runaway and Homeless Youth Program, the Transitional Living Program, and others; and foster the integration of services directed to these youth. This would be consistent with the Secretary's interest in promoting service integration.

Making headway against HIV infection among street youth will require testing a number of specialized approaches to service delivery and grant program design. As we have not had an opportunity to review CDC's plans for its FY 1991 initiative, we cannot be sure whether the initiative will incorporate these approaches. Therefore,

we recommend that PHS and OHDS include in their strategy, either as part of the CDC initiative or as an adjunct to it, evaluations of the following measures:

1. *The allowance of waivers to some categorical program requirements.* Such waivers could be helpful in developing service interventions which respond in a more efficient and effective manner to the multiple, interrelated needs of street youth. They might also provide a way to serve youth over age 18 if the alternative "adult" resources are not appropriate for older adolescents.
2. *The allocation of funds for local planning efforts and the requirement that further funding depend on demonstrated collaboration among service providers.* The Robert Wood Johnson Foundation has taken this approach recently with some apparent success. The intent is to foster cooperation among a diverse group of agencies and professionals who may be otherwise inclined to work independently or competitively.
3. *The use of a single coordinating or "anchor" agency within each community.* The designation of a single community focal point for organizing the service interventions can facilitate the most efficient and effective use of the limited resources available. Ideally, such a focal point would be designated through the collaborative efforts of the local service providers.
4. *The collocation of some services for street youth.* As we have noted, street youth are often quite resistant to established health and social services. To the extent that such services are immediately accessible to them, their readiness to use them and their opportunity to benefit from them may be enhanced.

COMMENTS ON THE DRAFT REPORT

We received comments on the draft report from the Public Health Service (PHS), the Office of Human Development Services (OHDS), and the Assistant Secretary for Planning and Evaluation (ASPE). In appendix A, we present the detailed comments from these Department of Health and Human Services (HHS) components, and our responses to the comments. These comments reflect general concurrence with the thrust of our findings and recommendations, and contain several suggestions and technical corrections relating to specific sections of the report. We have incorporated a number of these suggestions into the text.

We altered the final three recommendations in response to PHS's comments. The alterations to the recommendations for behavior change and HIV manifestation research were of a technical nature, and are explained in appendix A. The change to the final recommendation deserves further comment.

In the draft report, our final recommendation called for OHDS, in collaboration with PHS, to design and implement a five-city initiative to curb HIV infection among street youth. In concurring with that recommendation, PHS expressed the desire to take the lead for that initiative because its Centers for Disease Control (CDC) is already planning to implement a new six-city program with the same goal. Given the advent of this new initiative (which at the time of our draft report had not been funded), and given the lack of a comparable new initiative within OHDS, we have upon further reflection changed our recommendation to make it more compatible with PHS's existing plans. Specifically, we now call for PHS rather than OHDS to take the lead in implementing the new initiative, and call for the strategy to be implemented in six cities rather than five. We have also revised the text of the recommendation to highlight our feeling that certain components of the new strategy, which may or may not be in CDC's current plans, must be included on at least an experimental basis.

Both PHS and ASPE commented on our discussion of the National AIDS Program Office (NAPO). For reasons discussed in appendix A, we believe that an evaluation of NAPO's mission and performance may be in order.

APPENDIX A

DETAILED COMMENTS ON THE DRAFT REPORT AND OIG RESPONSE TO THE COMMENTS

In this appendix we present the full comments of all the parties that responded to the draft report and our response to each set of comments. We received comments on the draft report from the Public Health Service, the Office of Human Development Services, and the Assistant Secretary for Planning and Evaluation within the Department of Health and Human Services.



OCT 18 1990

Memorandum

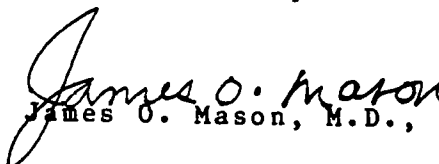
Date

From Assistant Secretary for Health

Subject OIG Draft Report "HIV Infection Among Street Youth,"
OEI-01-90-00500

To Inspector General, OS

Attached are the PHS comments on the subject report's findings and recommendations. We concur with the recommendations and have taken or plan to take actions to implement them. We suggest slight revision and re-wording of the last three recommendations in order to more appropriately elicit the scope of effort needed to address the report's findings.


James O. Mason, M.D., Dr.P.H.

Attachment

COMMENTS OF THE PUBLIC HEALTH SERVICE (PHS) ON THE
OFFICE OF INSPECTOR GENERAL (OIG) DRAFT REPORT "HIV
INFECTION AMONG STREET YOUTH," OEI-01-90-00500

General Comments

This draft report concludes that there is a relative dearth of Federal programs targeted to human immunodeficiency virus (HIV) infection and street youth. The term "street youth" encompasses several groups including homeless, runaway, and out of school youth. Although increased effort in this area can be justified, the report should take into consideration the significant number of Federal programs that are cross-cutting with respect to target populations, street youth being only one of them. Programs in many agencies may not be specifically titled "Street Youth," but may have notable impact on that population.

A list of programs, many of which are HIV related, specifically targeted to street youth was forwarded to OIG at the outset of its investigation. These programs have been included in a companion "directory of programs" to be released in the future. We believe that this directory should be included as an appendix in this report. It would be misleading to point out a dearth of programs in the Federal system and then at a latter date release a report with 50 or more Federal programs targeted to HIV and street youth.

The report interprets data from runaway and homeless shelters to indicate that many of the problems of street youth, such as physical and sexual abuse, emotional disturbance, and illegal drug use can be the cause or result of life on the streets. However, little in the recommendations addresses the "pre-street" phase where many factors combine, ultimately, to prompt a youth to enter street life. This report should recognize that programs to understand and intervene with troubled families, school-based detection programs, and other primary prevention activities need to be a priority also.

The National AIDS Program Office (NAPO) is portrayed as having limited effectiveness in coordinating the various PHS components because "it has no control over resource allocation or grant specifications." NAPO works directly with the PHS agencies and the Assistant Secretary for Health (ASH) in determining the priority areas for HIV funding on an annual basis, via the budget cycle. HIV planning initiatives and budget requests of the various agencies must first be submitted to NAPO for review. Based upon these reviews, NAPO makes funding recommendations directly to the ASH. Further, through the ASH, NAPO exercises its influence in program planning at the agency level throughout the year.

OIG Recommendation

1. PHS, through the Centers for Disease Control (CDC), should conduct additional seroprevalence research to measure the scope of the epidemic among street youth.

PHS Comment

We concur. Through CDC, the Department is already conducting seroprevalence research to measure the scope of the epidemic among street youth. CDC collects data from Job Corps entrants, sexually transmitted disease clinic clientele, women's health clinics, drug treatment centers, adolescent health centers, sentinel hospitals, family planning clinics, clinics that specifically serve homeless and street youth, juvenile detention centers, and other sources that collectively provide data about seroprevalence among high risk youth, including street youth.

In addition, CDC has planned an initiative to address street youth that is included in the President's fiscal year 1991 budget request. Through this initiative, CDC will assist local governmental and non-governmental agencies that serve street youth in six cities to plan, implement, coordinate, and evaluate studies of seroprevalence among street youth, the prevalence of risk behaviors among these youth, and of factors that influence the establishment of these behaviors.

OIG Recommendation

2. PHS should collect baseline data on the sexual behavior patterns of street youth.

PHS Comment

We concur. Through many different organizations and agencies that serve youth, CDC, and hence PHS, collects data about sexual and other risk behaviors of street youth that result in HIV infection. CDC provides fiscal and technical support to six national organizations to help youth-serving agencies provide HIV education for out-of-school youth. The National Network of Runaway Youth services is one of these organizations. CDC also directly funds 67 community-based organizations across the nation to provide HIV education to a variety of populations, including street youth. Of the 67 organizations, 44 target youth populations. Of these 44, 5 are working solely in schools, 39 are working with youth in various settings in the inner city, mostly minority communities, and 5 specifically target homeless or runaway youth.

In addition, a CDC initiative to address street youth that is included in the President's 1991 budget will assist local governmental and non-governmental agencies that serve street youth in six cities to plan, implement, coordinate, and evaluate the prevalence of risk behaviors among these youth, and the factors that influence the establishment of these behaviors.

Also, CDC's National Center for Health Statistics plans to conduct a household-based National Health Interview Survey Adolescent Supplement in 1992 to assess the comparative prevalence of the same risk behaviors among a national probability sample of school- and college-age youth who attend school or college, and those who do not.

OIG Recommendation

3. PHS, through the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), should conduct research on behavior change strategies designed to reduce the risk of HIV infection among street youth.

PHS Comment

We concur with the intent of the recommendation, but suggest that it be revised to encompass all PHS agencies. Since research to assess the effectiveness of behavior change strategies designed to reduce the risk of infections among various populations, including street youth, is being conducted by ADAMHA and CDC, we recommend that the recommendation be revised as follows:

"PHS should ensure collaboration among the various agencies that conduct research on behavioral change strategies designed to reduce the risk of HIV infection among street youth."

ADAMHA's efforts in this area have been well-documented. CDC has implemented several research and demonstration projects to evaluate behavioral change strategies designed to reduce the risk of HIV infection among street youth. In collaboration with the City of Chicago Department of Health, the Neon Street

Center for Youth provides services to homeless and runaway youth that incorporate HIV risk reduction messages in all center activities. Peer educators provide HIV education at the Neon Street drop-in center and on the streets. Behavior changes are assessed through initial and follow-up interviews conducted after a 2 month interval.

Through the Seattle Department of Health, community-based AIDS/HIV risk reduction interventions are being implemented in three hard-to-reach high risk groups, one of which is street youth. These youth are located primarily in two fairly isolated areas that can be used for comparison trials of intervention. The object of the study is to assess beliefs that interfere with adoption of safe sex and drug use behaviors.

A demonstration project is underway also in the City of Denver. This project is an ongoing follow-up of a cohort of 1,100 men who have had sex with men to assess seroconversion and changes in knowledge, attitudes, and behaviors. A cross sectional analysis will be conducted on the impact of pre- and post-intervention measures in three communities, one of which is youth at risk for HIV infection.

OIG Recommendation

4. PHS should conduct research on the manifestation of HIV infection in adolescents and develop appropriate clinical protocols for treating youth who are infected.

PHS Comment

We concur with the recommendation but believe that additional attention should be focused on the early and subclinical manifestations of HIV infection, the factors that determine occurrence of subclinical and clinical outcomes, and the factors that determine access to clinical care by street youth. We suggest, therefore, that this recommendation be revised as follows:

"PHS should conduct research on the natural history and manifestations of HIV infection in adolescents and develop appropriate counseling, testing and clinical protocols for youth who are infected."

Research should not be limited to the development of clinical protocols, but should include an examination of access to early intervention services by street youth. Clinical protocols, no matter how effective, are of limited use to street youth unless they have access to care.

OIG Recommendation

5. The Office of Human Development Services (OHDS), in collaboration with PHS, should design and implement a strategy to curb HIV infection among street youth in five cities with large populations of street youth and high rates of HIV infection.

PHS Comment

We concur. However, we believe that the recommendation, as written, could lead to unnecessary fragmentation in the overall coordination of the national AIDS/HIV prevention effort. Therefore, we suggest that this recommendation be revised as follows:

"OHDS should collaborate with PHS to design and implement strategies to curb HIV infection among street youth."

As noted on page 9 of the draft report, CDC has already planned an initiative specifically to prevent HIV infection among street youth in up to six cities with the highest cumulative incidence of AIDS. The President's budget for fiscal year 1991 requested \$5.2 million for CDC to implement this initiative. We believe that CDC should maintain lead responsibility for this effort. CDC will assist local governmental and non-governmental agencies that serve street youth in these cities to plan, implement, coordinate, and evaluate intensive efforts to prevent the spread of HIV infection among street youth.

During the past several years CDC has implemented six other interrelated national activities to prevent HIV infection among out-of-school youth, especially street youth. As a result, CDC has established significant capacity and experience to prevent the spread of HIV infection among this population. We believe that the best way to reach this population is through the combined and coordinated capabilities of multiple programs within CDC, as well as through other Federal and non-Federal agencies. CDC would be pleased to work with OHDS to implement this initiative.

Technical Comments

- Page 2 The acronym for the National Institute for Mental Health, NIMH, should be introduced here rather than on page 16.
- Page 9-10 The rates and raw numbers of Job Corps applicants infected with HIV in various cities do not reflect the size of the total populations in those cities (including the potential size of the street youth populations in those cities). The number of AIDS cases diagnosed within various cities is a function of both the rate of HIV infection within the cities and the size of the population at risk. Thus, the number of AIDS cases would be a better criterion to use for directing program efforts, than the raw numbers of Job Corps entrants infected with HIV.
- Pages 10 ADAMHA "divisions" should be changed to ADAMHA
and 20 "components."
- Page 11 Table 1 may be misleading and we recommend that it be deleted. The data are based on reports that are biased toward major manifestations apparent at the time of initial diagnosis of AIDS. These data do not reflect the clinical course of AIDS. The distributions may be statistically significant, but they are probably not clinically significant. Rather than reflecting a difference in the distribution of manifestations of AIDS between teenagers and adults, the table is likely to be a reflection of AIDS among teenagers with hemophilia compared to AIDS among adult gay males.
- Page 16 The acronym for NIDA should be used only after identifying it as the National Institute on Drug Abuse.
- Page 16 NIDA, OSAP, and NIMH should be identified as being components of ADAMHA.
- Page 19 The last sentence of the first paragraph could confuse readers as written. We suggest that it be revised as follows:
- "The long HIV incubation period means there will probably never be a comparatively large number of teenagers diagnosed with AIDS, no matter how many teens become infected with the virus. Many teens who become infected will not develop AIDS until they become adults."

OIG RESPONSE TO PHS COMMENTS

We thank the PHS for its thoughtful response and appreciate its concurrence with our recommendations. We have made the revisions to the third and fourth recommendations as suggested in the PHS comments.

As explained in the Comments section of the report, we have also revised the final recommendations in response to PHS's comments. We now call for the PHS to take lead responsibility for a six-city initiative and for PHS to collaborate in that effort with OHDS. We recognize that CDC's FY 1991 initiative presents a logical vehicle for implementation of our recommendation. Unfortunately, we have not been able to review a current and detailed plan for the CDC initiative, but we assume that it resembles the draft of a similar initiative which CDC hoped to implement during FY 1990. Our review of that draft leads us to believe that while CDC's planned initiative is certainly consistent with the intent of our recommendation, it may not be sufficient. Therefore, we have modified the text accompanying the recommendation to reflect our position in that regard. While we originally stated that the planners for the new strategy should consider taking four steps to reduce categorical program barriers at the service delivery level, we now include evaluation of those steps as an integral part of the new strategy. The steps we are referring to are the use of waivers to eliminate categorical barriers to service, linkage of funding to demonstrated collaboration among local service providers, the use of an anchor agency within each community, and collocation of services. We also stress that to satisfy the intent of our recommendation, CDC must include OHDS and other PHS components in the planning process and must encourage these other agencies to consider how their own future initiatives can supplement or complement CDC's.

We have incorporated the changes suggested in PHS's technical comments, with one exception: we do not agree that the number of AIDS cases is the best criterion for directing program efforts aimed at street youth. It is our belief that the problem of HIV infection among street youth may be manifested in a large number of metropolitan areas across the country and that the 2900-AIDS-case requirement proposed by CDC for its new initiative may exclude from consideration many cities with equal if not greater need. This belief stems in part from the Job Corps seroprevalence data we present in the report. We urge CDC to re-evaluate the eligibility criteria for cities wishing to apply for funding through CDC's new initiative.

Finally, we offer the following response to PHS's general comments:

Use of companion report: We agree that publication of the directory of programs at a later date would not be timely. We note that the companion report entitled, "HIV Infection Among Street Youth: Department of Health

and Human Services Programs and Resources," has already been published in final form and is currently available. We suggest that publication of the directory as a free-standing report, rather than an appendix to this report, enhances its visibility.

Broader prevention efforts: We concur with the PHS in its observation that prevention of problems that lead young people to live on the streets is a worthwhile goal. We would support the PHS in its desire to improve primary prevention programs for high-risk families and would welcome a request from PHS to evaluate its efforts in this regard.

The role of NAPO: We acknowledge that NAPO is given the opportunity to comment on allocation proposals. Nevertheless, based on our research for this study we concluded and maintain that NAPO has no clear authority to design or coordinate PHS program efforts. Furthermore, as the Assistant Secretary for Planning and Evaluation points out in his comments on this report, non-PHS components of the Department are insufficiently represented in NAPO-organized working groups. We believe that NAPO's current structural limitations hinder its ability to fulfill its mission and that NAPO's mandate itself may not be sufficiently broad to ensure coordination and prevent duplication within the Department. As this inspection was not designed as an evaluation of NAPO's mission or performance, and as we are not aware of any formal evaluations of NAPO, we are not making any formal recommendations to PHS regarding that office. Given, however, the critical nature of the epidemic, the visibility of the office, and the need for coordination of Departmental efforts to prevent the spread of HIV infection, such an evaluation may be in order.



SEP 30

TO: Richard P. Kusserow
Inspector General

FROM: Assistant Secretary
for Human Development Services

SUBJECT: Office of Inspector General Draft Report on "HIV
Infection Among Street Youth" (OEI-01-90-00500)

Thank you for the opportunity to review the draft report developed by the Office of Inspector General on "HIV Infection Among Street Youth." The report effectively describes the need for increased interagency efforts as well as research in order to better address the needs of street youth infected with human immunodeficiency virus (HIV). As such, it should be useful to policymakers both within and outside the Department of Health and Human Services. While we concur with the thrust of the report, we have several comments.

First, the report should advocate for coordination beyond that involving just the Public Health Service (PHS) and the Office of Human Development Services (OHDS). An examination of the extent to which the categorical programs administered by other Federal agencies, such as the Departments of Education and Labor, could be extended to serve this population is also needed. With respect to collaboration between OHDS and PHS, however, some efforts are already underway. In Region IX, for example, the two agencies are cooperatively developing a data collection effort to assess the health and medical needs of runaway and homeless youth.

Second, while the report discusses barriers to the provision of needed services to street youth, such as the denial of eligibility for Medicaid benefits and the need for parental consent prior to treatment (pages 11-13), it does not address potential ways to remove these barriers. Street youth, because they are not in family settings, are in limbo and are ineligible for most Federal benefits to which many of them had previously been linked when residing with their natural, foster or other families. These programs include Titles IV-A (Aid to Families With Dependent Children), IV-B (Child Welfare Services),

IV-E (Foster Care) and, particularly relevant to street youth, XIX (Medicaid). Needed remedies include advocating for the extension of coverage for benefits such as Medicaid to this population and working with the States to liberalize emancipation requirements. Moreover, as the report describes, "'survival sex'" (and we would add drug abuse) are the behaviors which put street youth at high risk of HIV infection (page 5). If the basic needs of these youth for food, shelter and other assistance are met, we may be able to reduce these behaviors. And by linking street youth to Medicaid and by assuring that medical, psychological and psychiatric providers treat them if they are emancipated, the resistance to HIV testing by youth service workers may be reduced (page 7).

Third, while the report discusses the need for programs which are directed towards older street youth and which offer lengths of stay beyond thirty days (pages 12-13), no mention is made of programs, such as the new Transitional Living Program for Homeless Youth, which address these voids. Grants under the Transitional Living Program, to be awarded for the first time in fiscal year 1990, will support the provision of a wide range of services (including shelter, health promotion and treatment) to homeless youth, aged 16-21, for periods of up to eighteen months.

Again, thank you for the opportunity to review this report.


Mary Sheila Gall

OIG RESPONSE TO OHDS COMMENTS

We thank OHDS for reviewing our report and for its concurrence with our recommendations. We feel that OHDS has accurately identified the need for increased coordination within and outside DHHS, and for additional flexibility in the administration of assistance programs. We hope that our report can provide the impetus for future efforts by OHDS in these areas. In response to OHDS's third point, we point out that the Transitional Living Program is indeed mentioned at the end of the Introduction and in the text accompanying the final recommendation, as well as in the companion report, "HIV Infection Among Street Youth: Department of Health and Human Services Programs and Resources."



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Margaret H. Brennan
Center
Reg. I

SEP 7 1990

IG	✓
PDIG	✓
DIG-AS	
DIG-EI	✓
DIG-OI	
AIG-MP	✓
OGC/IG	
EX SEC	✓
DATE SENT	9/13

Washington, D.C. 20201

TO : Richard P. Kusserow
Inspector General

FROM : Assistant Secretary for
Planning and Evaluation

SUBJECT: OIG Draft Report: "HIV Infection Among Street Youth"
OEI-01-90-00500 -- COMMENT

1990 SEP 13 AM 11:03

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GENERAL

I appreciate the opportunity to review and comment on the above named report. I think that the report will prove useful in that it helps to bring greater attention to a group of youth who are at particular risk of HIV infection. In addition, I think the finding that "basic survival needs of street youth overwhelm education efforts aimed at reducing high-risk behavior" is particularly important, and encourage you to give greater emphasis to this finding and its relationship to your specific recommendations.

While this study reports remarkably high levels of knowledge among street youth about how to avoid HIV infection, many other studies have found that a high degree of ignorance about HIV infection exists among adolescents. This apparent inconsistency should be addressed, even though the main message is that knowledge alone is not sufficient to prevent high risk behavior in this population.

While HIV infection can be effectively prevented through the use of condoms and avoidance of high risk behaviors, these methods are not being effectively transmitted to street youth or other adolescents at high risk of infection. Therefore, I think one of the study's primary recommendations should be to encourage the research and development of educational strategies for adolescents that will change high risk behaviors.

I have several other comments, as well as some specific technical suggestions.

Comments

1. Reasons for Understanding the Impact and Future Threat of AIDS

The third paragraph on page 2 states that this is critical for two reasons: because of improving the chances of long-term survival due to recent medical breakthroughs and because a large number of street youth eventually return to

mainstream society, unknowingly spreading HIV infection. While these reasons are important, I think the primary reason should be to prevent HIV infection in this group and the general population.

I suggest retaining the first justification but only as a secondary reason. There is no way to make those who have contracted the virus "well" with medical treatment. The language that street youth may eventually return to mainstream society should be dropped because of the insensitivity it reflects for those with the disease. AIDS treatment and prevention should be provided to all groups without regard to their present or future contact with the "general" population, however that is defined.

2. Data Collection on High Risk Sexual Activity - On pages 8 and 19, the report recommends data collection on sexual activity of street youth. Surveying street youth on sexual activity has many of the same methodological difficulties as are cited under the discussion for seroprevalence studies. Consequently, the use of a national survey approach such as the "Survey on Health and AIDS Risk Prevalence," might prove to be very difficult. I agree with the recommendation that gathering data from several metropolitan areas with large concentrations of street youth is preferable to a national survey. This approach of performing in-depth studies at selected sites has been used to look at HIV risk behavior in IV drug abusing populations, another hard to reach population.
3. Case Management Versus Collocation - On pages 14 and 15, the report raises an interesting issue on the effectiveness of using case management versus collocation or "one stop shopping" in getting services to street youth. Is this an issue that merits further investigation, and one for which your office would recommend that further research be done?
4. Local Coordination - The first paragraph on page 14 is principally directed at fragmented funding streams. However, it is also an example of the need for localities to do better coordination.
5. HDS Representation on NAPO Coordinated Groups - I think that this study appropriately has identified a need for NAPO to better incorporate the non-PHS components of the Department in their coordinating activities. I suggest that you might want to make a specific recommendation related to this finding.
6. ADAMHA Designation of a Single Unit to Coordinate Research on Street Youth - I am concerned that, as now stated, the IG recommendation could be misinterpreted to mean the creation

of a new organizational entity or individual role. Research on street youth is not unique in needing collaboration and coordination. ADAMHA has many issues in which there is a need for coordination among its Institutes and Offices. If you think it is important to recommend a coordinating function, I suggest that you provide more flexibility to the ADAMHA Administrator to determine how to achieve that coordination.

Technical Comments

1. Page i and page 1, second paragraph. It would be more accurate if the background information spoke about the number of reported cases of AIDS among adolescents and those in the 20- to 29-year-old categories. The statement, "Although very few teenagers have developed AIDS, ..." should read, 'Although very few cases of AIDS have been reported among teenagers, the number of reported cases among 20- to 29-year-olds suggests a high level of HIV infection (which causes AIDS) among teenagers.'

While the general observations in the document regarding disease prevalence are probably true, it is likely that significant underreporting of both HIV infection and AIDS occurs in these age groups, and it would be preferable to use the more precise language in the background statement.

2. Page 1, third paragraph. As now drafted, the paragraph potentially could give the impression that the 13- 29-year olds with AIDS are not predominantly male. Yet the data in the endnotes indicate that even in the younger age groups males are significantly overrepresented. This discussion, combined with the use of the female gender pronouns or female examples when discussing the street youth, gives the impression that female street youth are more at risk.
3. Page 6, first paragraph. The phrase "we heard anecdotal evidence from providers in several cities that their clients are willing to pay more for sex without condoms ..." perhaps needs redrafting. As currently written, it implies that the street youth, themselves, are willing to pay more for sex without condoms. Is this the intent of this sentence?
4. Page 10, "Treatment Protocols." While representation of adolescents in clinical trials is a legitimate concern, the paragraph should point out that one of the obstacles has been the size of the pool of potential participants.

5. Page 13, "Other Conditions of Participation." As now drafted, the paragraph implies that the youth was excluded from the treatment program because she did not have a supportive partner. Is this in fact the case, or is it that the girl did not successfully complete treatment? This point needs clarification because many substance abusers drop out of treatment programs. If the young girl was admitted to the program but did not successfully complete treatment, then this particular requirement is not a good example of program requirements that may be barriers to street youth.



Martin H. Gerry

OIG RESPONSE TO ASPE COMMENTS

We thank the Assistant Secretary for his thoughtful comments and his support for recommendations contained in our report. We agree about the importance of our finding that the basic survival needs of street youth overwhelm education efforts geared to reducing high-risk behavior. Our final recommendation is aimed at addressing the issue of basic survival needs. Our hope is that by restructuring services and using waivers to eliminate access barriers, the Department will be able to address the basic needs of street youth more effectively. We also concur about the value of educational strategies to change high-risk behaviors among adolescents. Our third recommendation directed to the PHS addresses this issue specifically.

We have made nearly all the changes suggested in the Assistant Secretary's general and technical comments. We strongly agree with the concern about the need for NAPO to better incorporate the non-PHS components of the Department in its coordinating activities. We suggest in our response to PHS's comments that a formal evaluation of NAPO's mission and performance may be in order.

APPENDIX B

METHODOLOGICAL NOTES

The methodology for the study included the following:

1. *Literature review.* The study team conducted a literature review of popular, professional and government publications. We reviewed articles and reports on issues such as epidemiology; behavior modification models; HIV education, prevention, and intervention; adolescent health; HIV knowledge, attitudes, beliefs and behaviors; and clinical treatment.
2. *Federal survey.* The study team examined current Federal policy and actions on the issue of HIV infection among street youth through a review of Departmental documents and interviews with relevant staff in offices engaged in AIDS-related activities.

In response to a formal request for information, eight Departmental offices provided a summary of ongoing activities relevant to HIV infection among adolescents for our review. Six other offices added supplemental information. We relied on the documents to formulate a profile of Departmental efforts and looked for signs of internal duplication and omissions.

Following a review of these documents, we conducted interviews with 15 Federal employees who had significant experience with either HIV infection or street youth or both. The interviews garnered information on: the employees' perceptions of the strengths and weaknesses of Departmental efforts; suggestions for strengthening the Department's overall approach; coordination of activities within the Department; and mechanisms for sharing of information among offices and divisions.

We analyzed the qualitative data collected in interviews with Departmental staff to identify barriers to communication and coordination within and among organizational components and ways to enhance collaboration. We reviewed Departmental efforts and strategies in the context of major research findings and lessons learned at the service delivery level.

3. *Research and advocacy organization survey.* Telephone interviews were conducted with officials from 2 local and 13 national independent organizations who perform research and provide advocacy services. The organizations selected either receive Federal funding for HIV-related activities, or were identified through the literature or word-of-mouth as playing a major role in this area.

The discussion guide used for the telephone interviews elicited information on such issues as coordination among advocacy and direct service organizations on the issue of HIV infection; their stance on HIV testing; their perceptions of the Federal response to HIV among street youth; and their ideas about successful prevention, testing, and treatment programs for this population.

4. *Direct service provider survey.* Information was obtained from direct service providers that serve street youth, through a telephone survey of 20 organizations and site visits to 3 selected providers. The Office of Human Development Services provided a list of candidates for the survey. From this list we selected 23 organizations on the basis of caseload size and geographical diversity (each region of the country yielded at least 2 participants). The site visits took place in three major urban areas with a relatively large population of street youth and a selection of programs that serve them.

We conducted the telephone interviews with the executive directors of these organizations, or their designees. A discussion guide was used to ask them about issues that affect service delivery for street youth; lessons learned from experiences with service delivery; and perceptions of Federal efforts. A protocol, incorporating the issues covered in the telephone interview and elaborating upon them, was used for the site visits.

The telephone interviews and site visits were used to develop profiles of programs that are providing innovative services, to create an inventory of positive and negative lessons learned at the service delivery level, and to identify areas of consensus regarding opportunities to improve Departmental efforts.

A list of participating offices and organizations follows:

Federal offices responding to a formal request for information: Alcohol, Drug Abuse, and Mental Health Administration; Centers for Disease Control; Food and Drug Administration; Health Resources and Services Administration; Health Care Financing Administration; National AIDS Program Office; National Institutes of Health; and Office of Human Development Services.

Offices providing supplemental information: Bureau of Prisons; Indian Health Service; Job Corps; Office of Assistant Secretary of Defense for Health Affairs; Office of Disease Prevention and Health Promotion; and Office of Minority Health.

National and local research and advocacy organizations: American Foundation for AIDS Research; Association for the Care of Children's Health; Boston AIDS Consortium; Center for Population Options; National AIDS Network; National

Coalition of Advocates for Students; National Coalition of Hispanic Health and Human Services Organizations; National Commission on Correctional Health Care; National Education Agency/Health Information Network; National Minority AIDS Council; National Network of Runaway and Youth Services; National Organization of Black County Officials; Planned Parenthood (of Washington, D.C.); Society for Adolescent Medicine; and U.S. Conference of Mayors.

Direct service organizations: Adolescent AIDS Program, Bronx, NY; Avance Human Services, Los Angeles, CA; Bridge Over Troubled Waters, Boston, MA; Casa Shelter YMCA, Dallas, TX; Comitis Crisis Center, Aurora, CO; Covenant House, Ft. Lauderdale, FL; The Door, New York, NY; Gay and Lesbian Community Service Center, Los Angeles, CA; Janice Youth Programs, Portland, OR; L.A. Children's Hospital, Los Angeles, CA; L.A. Network, Los Angeles, CA; Larkin Street, San Francisco, CA; Middle Earth Unlimited, Austin, TX; Neon Street Shelter, Chicago, IL; New Beginnings, Lewiston, ME; Sasha Bruce Youthworks, Washington, DC; Streetwork Project, New York, NY; Synergy House, Parkville, MO; Teen Living, Chicago, IL; Volunteers of America, Denver, CO; Youth Care, Seattle, WA; Youth Emergency, Philadelphia, PA; and Youth Emergency Shelter and Services, Des Moines, IA.

APPENDIX C

ENDNOTES

1. Centers for Disease Control, *HIV/AIDS Surveillance Report*, November 1990. Figures through October 31, 1990. Teenagers represent less than 0.4 percent of the total number of AIDS cases.
2. Centers for Disease Control, *Strategic Plan for the Prevention of Human Immunodeficiency Virus (HIV) Infection: 1990 and Beyond (Draft)*, Centers for Disease Control, 1990. For adolescent vs. adult incubation period, see Goedert, J.J., et al., "A Prospective Study of Human Immunodeficiency Virus Type 1 Infection and the Development of AIDS in Subjects with Hemophilia," *New England Journal of Medicine* 321(17):1141-1148, 1989.
3. Centers for Disease Control, *HIV/AIDS Surveillance Report*, November 1990. Figures through October 31, 1990.
4. See, for example, U. S. General Accounting Office, *Homelessness: Homeless and Runaway Youth Receiving Services at Federally Funded Shelters*, HRD-90-45, December 1989.
5. A runaway youth is a person under 18 years old who absents himself or herself from home or place of legal residence without the permission of parents or legal guardians. A homeless youth is a person under 18 years old who is in need of services and without a place of shelter where he or she can receive supervision and care. See *Federal Register* 55(44):8086, March 6, 1990.
6. Figures from the National Network of Runaway and Youth Services, cited in U. S. General Accounting Office, *AIDS Education: Programs for Out-of-school Youth Slowly Evolving*, HRD-90-111, May 1990, p. 2.
7. The Department of Defense, whose test results are often cited as evidence of the infection rate among young Americans, has actually witnessed a decline in the incidence of HIV antibodies among applicants since 1985. This may be due, however, to self-selection bias caused by knowledge of HIV testing requirements and by recent publicity surrounding DoD's policy of excluding homosexuals from military service. Furthermore, the military is not likely to attract many street youth. Unlike military recruits, 97 percent of all Job Corps entrants are under 21 years old and are primarily from low-income families and urban settings. Although the Job Corps sample certainly taps the street youth population more regularly than the military sample, it too may underestimate the true incidence of

HIV among street youth. The Job Corps's testing requirements are also well known, and the Corps tests only those street youth who are motivated to enter a strictly regimented program.

8. Response to OIG request from Deputy Director (HIV), Centers for Disease Control, May 1990. These estimates are derived from seroprevalence data gathered at 26 sentinel hospitals, which are part of CDC's efforts to determine the progress of the epidemic nationwide. The CDC was unable to provide any demographic information other than age range and sex to accompany this estimate.
9. For a review of published epidemiological data concerning AIDS, HIV, and adolescents, see National Research Council Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences, *AIDS: The Second Decade*, Washington: National Academy Press, 1990, pp. 147-167.
10. Between October and December 1989, military recruits tested positive for HIV at a rate of 0.2/1,000 for 17- to 20-year-olds, and 1.6/1,000 for 21- to 25-year-olds. For Hispanic 17- to 20-year-old males, however, the rate was 1.2/1,000, and for black 21- to 25-year-old males, the rate was 6.2/1,000. Figures provided in response to OIG request from Office of Assistant Secretary of Defense for Health Affairs, Department of Defense, March 1990.
11. While the seroprevalence rate for Job Corps applicants nationwide between October 1, 1987, and October 31, 1989, was 3.88/1,000, several cities experienced much higher rates. Examples include San Francisco (13.91/1,000), Miami (12.98/1,000), and New York City (10.42/1,000). Figures provided in response to OIG request from Director, Office of Job Corps, Department of Labor, March 1990.
12. According to the Public Health Service's draft of the *Year 2000 National Health Objectives*, 1987 seroprevalence rates among 18- to 25-year-old homosexual men seeking treatment for sexually transmitted diseases were as high as 700/1,000, while for people in the same age group seeking treatment for intravenous drug use they ranged up to 600/1,000. Preliminary data from a seroprevalence survey of homeless youth in New York City, provided to us by CDC's Center for Infectious Diseases, indicate an infection rate of 70/1,000.
13. Brooks-Gunn, J., Boyer, C.B., and Hein, K., "Preventing HIV Infection and AIDS in Children and Adolescents: Behavioral Research and Intervention Strategies," *American Psychologist* 43(11):958-964, 1988.
14. Non-IV substance abuse, while not considered risky for HIV transmission in itself, is thought to stimulate sexual activity and interfere with the cognitive functioning necessary for safer sex.

15. This is a weighted average, with weight added in proportion to the number of clients served.
16. Personal communication with Diane Sondheimer, National Institute of Mental Health, March 1990.
17. Becker, M.H., and Joseph, J.G., "AIDS and Behavioral Change to Reduce Risk: A Review," *American Journal of Public Health* 78(4):394-410, 1988.
18. National Institute on Drug Abuse, *AIDS High Risk Adolescent Prevention Project: Participant's Manual*, n.d., pp. 2-10.
19. Ibid.
20. Wright, J.D., "Poverty, Homelessness, Health, Nutrition and Children," unpublished paper delivered at conference on *Homeless Children and Youth: Coping with a National Tragedy*, Washington, D.C., May 1989.
21. National Institute of Allergy and Infectious Diseases, "Recommendations for Zidovudine: Early Infection," *JAMA* 263(12):1606-1609, 1990.
22. Goodman, E., and Cohall, A.T., "Acquired Immunodeficiency Syndrome and Adolescents: Knowledge, Attitudes, Beliefs, and Behaviors in a New York City Adolescent Minority Population," *Pediatrics* 84(1):36-42, 1989.
23. Athey, Jean, "HIV Infection and Homeless Adolescents," unpublished manuscript, 1990, p. 7.
24. Ibid.
25. Brooks-Gunn, J., and Furstenberg, F.F., "Adolescent Sexual Behavior," *American Psychologist* 44(2):249-257, 1989.
26. D'Angelo, L.J., and Sondheimer, D.L., "Adolescents and HIV Infection: Struggling Not to Be Forgotten," *Pediatric AIDS*, in press. See also the Office of Technology Assessment Staff Paper, *How Effective is AIDS Education?*, 1988.
27. Flora, J.A., and Thoresen, C.E., "Reducing the Risk of AIDS in Adolescents," *American Psychologist*, 43(11):965-970, 1988.
28. Watkins, J.D., et al., *Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*, 1988, p. 3.
29. Pediatric AIDS Coalition, *1990 Legislative Agenda*, p. 12.

30. Personal communication with Diane Sondheimer, National Institute of Mental Health, May 1990.
31. Ibid.
32. English, A., "Adolescents and AIDS: Legal and Ethical Questions Multiply," in Quackenbush, M., Nelson, M., and Clark, K., *The AIDS Challenge, Prevention Education for Young People*, Santa Cruz, CA: Network Publications, 1988.
33. Yates, G., Testimony before the Little Hoover Commission on California State Government Organization & Economy, December 13, 1989. Also personal communication with Gary Yates, March 1990.
34. For the purposes of this question, we considered each major component of the Public Health Service plus OHDS and HCFA to be a separate agency. Subcomponents such as the National Institute of Mental Health and the National Institute on Drug Abuse were not considered separate agencies.
35. The particular agencies named most often were CDC (11 mentions), ADAMHA (5 mentions), and NIH (5 mentions).
36. Here the most commonly cited agencies were CDC (10 mentions), ADAMHA (7 mentions), HRSA (4 mentions), NIH (4 mentions), and OHDS (3 mentions).
37. National AIDS Program Office, unpublished document, June 1989.
38. *Federal Register* 55(92):19832-39, May 11, 1990.
39. Now that both have been completed and are being implemented across the country, OHDS is making efforts to ensure coordination between agencies and contractors.
40. U.S. General Accounting Office, *AIDS Education: Programs for Out-of-School Youth Slowly Evolving*, HRD-90-111, May 1990, p. 1.
41. We asked for ratings of the overall response on a scale of 1-10, with 1 meaning poor and 10 meaning excellent. The mean responses were as follows: From direct service providers, 2.4 for street youth and 3.4 for youth in general; from research and advocacy organizations, 2.4 for street youth and 4.0 for youth in general; from DHHS officials, 3.7 for street youth and 5.9 for youth in general.