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AIDS

Delivering and Financing Health Services in Five Communities

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The Honorable Edward M. Kennedy
Chairman, Committee on Labor
  and Human Resources
United States Senate

The Honorable Henry A. Waxman
Chairman, Subcommittee on Health
  and the Environment
Committee on Energy and Commerce
House of Representatives

This report examines the availability of health and social services for people with acquired immunodeficiency syndrome (AIDS) in five communities. Although AIDS is spreading across the country, little is known about how communities other than New York City and San Francisco are delivering and financing care for people with AIDS. Therefore, we visited state and local officials and other health experts in New Haven, Baltimore, Philadelphia, New Orleans, and Seattle to begin to ascertain how they are dealing with the AIDS epidemic.

We are sending copies of this report to the Secretary of Health and Human Services and other interested parties. Major contributors to the report are listed in appendix II.

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Executive Summary

Purpose

Acquired immunodeficiency syndrome (AIDS) is a relatively new and incurable infectious disease with profound implications for health care delivery, financing, and public policy. Since AIDS was first identified in 1981, nearly 100,000 people have been diagnosed with the disease and more than 55,000 have died. By the end of 1992, the Public Health Service predicts that 365,000 people will have been diagnosed with AIDS and 263,000 of them will have died. Medical care costs related to AIDS are projected in the range of $5 to $13 billion in 1992.

Not only is the AIDS epidemic continuing to spread, but the patient population is expanding to include more intravenous (IV) drug users, minorities, women, and children. And, as medical science progresses, people with AIDS are living longer and requiring more chronic care services.

At the same time, AIDS is spreading geographically to hundreds of smaller American cities. Little is known, however, about how communities outside New York City and San Francisco finance and deliver care to people with AIDS. To help fill this information void, GAO examined AIDS health services in five communities—New Haven (Connecticut), Philadelphia, Baltimore, New Orleans, and Seattle. The review focused on:

- how the communities delivered and financed health services for people with AIDS, and
- the federal implications of community and state actions.

Background

AIDS is the final stage of a disease process caused by the human immunodeficiency virus (HIV). As a result of damage to the immune system caused by HIV, people with AIDS are vulnerable to a wide range of life-threatening infections and cancers. The health care needs of AIDS patients vary widely depending on multiple medical problems and the stage of illness. For example, AIDS patients may need acute care in a hospital, regular treatment through outpatient clinics, or chronic care in an institution or at home during the course of the disease.

The federal government has invested most of its AIDS funding in biomedical research, education, and prevention activities. Viewed largely as a state and local responsibility, service delivery has received much less federal support. Instead, most federal dollars for patient care have been spent on Medicaid recipients with AIDS.

Results in Brief

The federal government, through the Medicaid program, pays at least 25 percent of the nation's AIDS medical care bill. In communities like San Francisco, high-quality care is available at lower cost than in other cities because alternatives, such as home and community-based services, substitute for hospital-based care. As the epidemic progresses across the country, Medicaid as well as private insurers will pay for more expensive AIDS health services if communities have not developed lower-cost alternative delivery systems. Therefore, the federal government has a strong financial incentive to encourage less costly, quality-conscious AIDS delivery systems.

GAO's review indicates that communities will experience different problems in providing AIDS services. Over the next several years, many communities will need help developing and coordinating health services to meet the needs of their growing AIDS caseloads. Modest federal and private demonstration projects, such as those now underway in some cities, allow communities broad flexibility to develop alternative services tailored to their unique needs. Expanded assistance to more communities and wide dissemination of results from AIDS-related demonstration projects have the potential to help many communities replicate successful AIDS delivery systems or create their own. Such assistance and sharing of information can help to control the costs of caring for people with AIDS.

GAO's Analysis

GAO reviewed AIDS population characteristics, service availability, and payment for services in five communities. Demand for certain AIDS services in some communities already has exceeded capacity, and other services were not available at all.

Growing AIDS Populations Differ

The size of the AIDS populations of the five communities had doubled nearly every year since 1981. Nationwide AIDS statistics tended to mask the uniqueness of AIDS populations in individual communities, which ranged from those made up almost exclusively of homosexuals to those predominantly made up of or related to IV drug users. Racial characteristics of the AIDS populations also varied considerably among the communities. Most cities, even those with primarily homosexual AIDS populations, expected growth in their IV drug cases. (See ch. 2.)

Service Gaps Remain

The availability and adequacy of health services for people with AIDS varied according to the nature of the communities' AIDS populations and their health resources. (See ch. 3.)

- Hospital care was generally available for people with AIDS. Increasing AIDS caseloads were straining inpatient capacity, however, in part because only a few hospitals in each community were treating AIDS patients. (See pp. 28 to 29.)
- Outpatient medical care provided by physicians and clinics was reaching capacity, and some clinics had waiting lists. (See pp. 30 to 33.)
- In most of the communities, nursing homes did not admit people with AIDS because of limited capacity, lack of facilities and staff to care for infectious patients, and low Medicaid reimbursements. (See pp. 33 to 37.)
- Many home and community-based services were not available to AIDS patients who needed them because both capacity and insurance coverage were limited. These services included home nursing and attendant care, case management, mental health services, substance abuse treatment, and dental care. (See pp. 36 to 42 and 32 to 33.)
- The lack of housing for AIDS patients was a serious problem in all five communities. (See pp. 42 to 43.)

Medicaid Is Leading Payer

Although data on AIDS care costs and financing were poor, it appeared that Medicaid paid for 30 to 50 percent of AIDS hospitalizations in the five communities. In some communities, Medicaid's share may be increasing. As the epidemic grows and affects increasing numbers of IV drug users, minorities, women, and children, state and federal governments can expect increasing Medicaid expenditures for AIDS care. (See ch. 4.)

State Medicaid programs are complex systems for AIDS patients to negotiate, as they are for other recipients. Government and health officials in the five communities reported problems with eligibility, limited service coverage, and low reimbursement rates that in some cases prevented Medicaid programs from serving AIDS patients as effectively as possible. These problems were not unique to AIDS patients, but sometimes were accentuated for them. (See pp. 48 to 54.)

Recommendations

This report contains no recommendations.

Agency Comments

GAO did not request official agency comments on a draft of this report. However, key officials and providers from the communities that GAO studied reviewed draft summaries of findings for their sites, and their views have been incorporated in the report where appropriate.

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Abbreviations

AFDC	Aid to Families with Dependent Children
AIDS	acquired immunodeficiency syndrome
AZT	azidothymidine or zidovudine
CDC	Centers for Disease Control
DRG	diagnosis related group
HCBS	home and community-based services
HCFA	Health Care Financing Administration
HERO	Health Education Resource Organization
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
IV	intravenous
PHS	Public Health Service
RWJF	Robert Wood Johnson Foundation
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

Chapter 1

Introduction

Human immunodeficiency virus (HIV) disease, of which acquired immunodeficiency syndrome (AIDS) is the end stage, is a serious, rapidly growing public health problem in the United States. First, HIV infection is spreading throughout the country to smaller communities that have had little experience with the epidemic. Second, national statistics show an increasing proportion of cases among intravenous (IV) drug users and their sexual partners and offspring—people who are more likely to be uninsured. Finally, although there is no cure for the disease, emerging treatment patterns (including antiviral drugs and rigorous medical monitoring to prevent and treat infections) are prolonging life for some people with AIDS who in turn require more long-term care and outpatient services for chronic HIV disease.

The combined effect of these trends places new demands on health service delivery and strains already overburdened public financing systems in many locations. Outside New York City and San Francisco, however, little is known about how communities are responding to the epidemic and providing patient care services for people with AIDS. Specifically, the President's Commission on the HIV Epidemic, the National Academy of Sciences' Institute of Medicine, and other health experts have noted the serious and persistent lack of data and research about the need for AIDS services, appropriate settings of care, and service costs across the country.

To develop information on local and state responses to the AIDS crisis and analyze the implications of these responses for federal policies and expenditures, we reviewed five U.S. communities that had relatively large AIDS populations but were considered to be in the second wave of the epidemic.[1] These were New Haven, Connecticut; Philadelphia; Baltimore; New Orleans; and the Seattle-King County area of Washington.

Background

The AIDS epidemic is a serious national public health problem, and it is getting worse. Through the end of May 1989, the Centers for Disease Control (CDC) reported nearly 100,000 cases of AIDS and more than 55,000 deaths since the epidemic was recognized in 1981. The Public Health Service (PHS) predicted in 1988 that as many as 365,000 AIDS cases may be reported by the end of 1992, and, at that time, 1 to 1.5 million Americans may be infected with HIV. Research suggests that at

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[1] AIDS first hit hardest in New York City, San Francisco, Los Angeles, and Miami. The second wave of the epidemic refers to cities with smaller but significant AIDS caseloads.

least 50 percent, and perhaps all of those infected, eventually will develop AIDS.

AIDS has not spread evenly through the population, but has disproportionately affected young men, minorities,[2] and people at risk—homosexual and bisexual men or IV drug users. Between 1981 and the end of May 1989, 61 percent of the reported cases have been diagnosed in homosexuals; 20 percent in IV drug users; 7 percent in homosexuals who use IV drugs; and 5 percent in heterosexuals.[3] Over 70 percent of the homosexual cases were white men. Nearly one-half of all AIDS cases reported to CDC through May 1989 were diagnosed in people 30 to 39 years old.

CDC surveillance data also show that although women now comprise almost 10 percent of AIDS cases, nationwide about one-half of them were infected through their own IV drug use and nearly 30 percent contracted AIDS through sexual contact with infected men who most often were IV drug users. Eighty percent of IV drug-related AIDS cases have been found among minorities, and most women (73 percent) and children (77 percent) with AIDS are minorities. They are much less likely to have adequate access to primary health services, including prenatal care, and more likely to be uninsured or on Medicaid.

Medicaid is already the leading public payer for AIDS care and covers about 40 percent of AIDS patients at some time in the course of their illness. According to estimates prepared by the Health Care Financing Administration (HCFA),[4] the program pays about 25 percent of the nation's AIDS health care bills. The federal Medicaid share for AIDS care is estimated at $490 million for fiscal year 1989, and could reach $870 million by 1991.[5]

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[2] Blacks and Hispanics are overrepresented in the national AIDS population, relative to their shares of the general population. As 12 percent of the general population, according to the 1980 census, blacks make up 27 percent of cumulative AIDS cases reported to CDC through May 1989. Hispanics, as 6 percent of the 1980 general population, account for 15 percent of the cumulative cases.

[3] Of the remaining cases, 2 percent have been transmitted through transfusion of blood or blood products. Since 1985, screening of the blood supply and treatment of plasma products have significantly reduced such HIV transmission. In about 3 percent of all cases, the means of transmission cannot be determined.

[4] These estimates are based on extrapolations from Medicaid beneficiary and AIDS patient characteristics, not on Medicaid claims data, according to HCFA's Office of the Actuary.

[5] HCFA estimates federal and state Medicaid expenditures for AIDS care in fiscal year 1989 will be $950 million ($490 million federal, $460 million state) and in fiscal year 1991, $1.69 billion ($870 million federal, $820 million state).

AIDS Spreading to Smaller Communities Throughout the United States

Major urban areas have been hardest hit by the AIDS epidemic, but hundreds of midsize and smaller U.S. communities that have had little experience with the epidemic can expect to face the problems of AIDS in the near future. Before 1985, 44 percent of all U.S. cases were diagnosed in the New York City or San Francisco metropolitan areas; but in 1986, the proportion fell to 31 percent, and in 1987 and 1988, to 25 percent, according to PHS. By 1991, PHS expects that 80 percent of new AIDS cases will be reported in communities outside New York City and San Francisco.

The overwhelming response to the second Robert Wood Johnson Foundation (RWJF)[6] AIDS grant program in 1988—AIDS Prevention and Service Projects—indicates that many communities of all sizes are now aware of the need to prepare for AIDS. The foundation received over 1,000 AIDS project proposals from 48 states, 2 territories, and the District of Columbia, requesting a total of $537 million. Eighty-three percent of the applications came from outside the New York, San Francisco, and Los Angeles metropolitan areas. Many came from much smaller communities, such as Statesboro, Georgia; Ames, Iowa; and Fargo, North Dakota.[7] Including its AIDS service demonstration grants awarded in 1986, RWJF has provided about $44 million for AIDS services delivery in communities across the country.

IV Drug-Related AIDS Cases Increasing

Although homosexual men were the first population group in the United States to be severely affected by AIDS, the disease is increasingly being spread through IV drug use. Subsequent transmission from drug users to their heterosexual partners has also been well-documented. Outside of IV drug users, however, relatively few AIDS cases (about 5 percent) in the United States so far have been spread heterosexually. Public health experts are tracking epidemiological trends, which neither preclude nor predict a major heterosexual epidemic.

Of all AIDS cases reported to CDC in the United States from 1981 through June 1988, 19 percent were people whose only risk factor was IV drug use. But for new cases reported from June 1988 through May 1989, 23

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[6] RWJF in Princeton, New Jersey, is the nation's largest health care philanthropy.

[7] The AIDS response was the largest in RWJF's 15-year history. The requests for $537 million equaled more than one-half of the PHS AIDS budget for fiscal 1988, and more than five times the amount RWJF awards annually to improve health care for such groups as the elderly, the homeless, the mentally ill, infants, and other populations in the United States. The foundation's president said "The response reveals what is, in effect, a national assessment of community needs in the fight against AIDS." AIDS/HIV Record, Vol. 2 (Aug. 17, 1988), p. 2.

percent were in IV drug users. Health experts are concerned that the rate of HIV infection among drug users may continue to increase. A recent review of HIV infection in IV drug users indicates that 60 percent of IV drug users in New York City, and nearly 30 percent in central New Jersey and Baltimore, have already been infected with the virus.

Public health officials are worried that the crack cocaine crisis may also be contributing to the spread of HIV. As indiscriminate sexual activity and prostitution related to crack drug habits become more prevalent, officials are especially concerned that the spread of HIV may increase in the heterosexual population.

The occurrence of pediatric AIDS and HIV infection is increasing as more women of childbearing age become infected through their own or their sexual partners' drug use. Through May 1989, nearly 1,300 (79 percent) of the AIDS cases in children under 13 years of age reported to CDC were related to parental risk factors. Children account for 1.7 percent of all AIDS cases reported nationwide. Fifty-three percent of children with AIDS are black; 23 percent Hispanic; and 23 percent white. Infants and young children have been among the most difficult and expensive AIDS cases to treat.

Cost of New Treatments for AIDS Care Likely to Increase

Early in the epidemic, people with AIDS tended to be treated aggressively in research hospitals where they had relatively long stays. Consequently, estimates of lifetime hospital costs for AIDS cases reported through May 1985 were as high as $147,000 per patient. With reduced hospitalization and increased outpatient care, average treatment costs per AIDS patient have declined.

Current estimates are in the range of $50,000 to $60,000 average lifetime medical costs per patient, nationwide. When many services have been supplied by volunteers, as has been the case in San Francisco, reported lifetime costs have been as low as $30,000 to $35,000 per patient. But as the epidemic spreads to areas where community-based groups are less organized or as the capacity for volunteers to meet the demands of AIDS patients is exhausted, these services will have to be provided through the marketplace or not at all. Future trends in AIDS care costs are difficult to predict because the natural history of the disease and medical treatment options are changing dynamically. Assuming no medical advances that reduce the costs of care, however, sheer growth in the number of cases will drive total treatment expenditures upward over the foreseeable future.

National forecasts of the costs of AIDS medical care depend on caseload projections; but, based on PHS's 1988 projection of 365,000 cumulative cases by 1992, medical care costs in that year will be in the range of $5 to $13 billion. Medical costs, however, are overwhelmed by the indirect costs of productivity losses associated with premature death of people in their prime working years. According to a CDC-funded cost study in 1987, annual indirect costs could exceed $55 billion in 1991.[8]

AIDS and HIV treatment protocols are developing rapidly. Because no cure for AIDS is in sight, however, long-term palliative treatment, even on an outpatient basis, will probably add to the unavoidably high costs of the terminal stage of AIDS. For some, who may develop both cancer and dementia resembling Alzheimer's disease, AIDS care will be especially costly in both its acute and chronic care phases.

As AIDS patients live longer, they are more likely to exhaust their private insurance and turn to Medicaid or,[9] alternatively, become eligible for Medicare benefits through the Social Security Disability Insurance (SSDI) program. Few AIDS patients have survived through the 2-year waiting period to qualify for Medicare benefits. New data from Seattle and elsewhere, however, indicate that AIDS patients are living longer and more of them, although under 65 years old, may become Medicare beneficiaries.[10] It is too early to project the potential effects of AIDS on the Medicare program.

Objectives, Scope, and Methodology

Objectives

Basic information on how most communities have financed and delivered health services to people with AIDS has been scarce. With the exception of studies of New York City, San Francisco, Los Angeles, and

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[8] Scitovsky, Anne A., and Dorothy Rice, "Estimates of the Direct and Indirect Economic Costs of Acquired Immune Deficiency Syndrome," Public Health Reports, Vol. 102 (Jan.-Feb. 1987), pp. 1-17.

[9] People with HIV infection meeting CDC's definition of AIDS are presumed to be disabled and thus are eligible for Supplemental Security Income (SSI), which in turn qualifies recipients for Medicaid benefits in many states.

[10] About one-half of persons with AIDS in the Seattle-King County area who were diagnosed in 1987 will survive at least 20 months before death.

Miami—the four cities initially hit hardest by the epidemic—little has been reported on the effects of growing AIDS caseloads.

We reviewed AIDS service delivery and financing in five communities experiencing the second wave of the epidemic. These communities reflected a broad range of state and local responses. Our objectives were to examine the (1) responses of cities and states to the challenge of providing health services to people with AIDS and (2) federal implications of community and state actions. Specifically, we

- reviewed factors affecting each community's response to AIDS, especially AIDS population characteristics;
- compared how the five communities developed AIDS service systems; and
- identified the availability and adequacy of nonhospital services.

We also explored the potential implications for federal programs and policies by

- reviewing how Medicaid programs serve people with AIDS, and
- identifying public and private sector interventions designed to deliver quality care at lower cost.

Scope

To develop data from relatively in-depth case studies, we limited our review to five communities—New Haven, Connecticut; Philadelphia; Baltimore; New Orleans; and the Seattle-King County area of Washington. Although these communities all have relatively large caseloads, they vary with regard to geographic location and population size; AIDS caseload size and transmission characteristics; supply of health resources; sources of payment, including Medicaid programs and public hospitals; and the availability of supplemental public and private funding for AIDS service projects.

Like most AIDS researchers, we used AIDS case counts from the CDC AIDS surveillance system because these counts were the most consistent and accurate figures available. AIDS experts, however, are increasingly using broader terms, such as "HIV disease" and "HIV infection," to represent the full range of the disease. It is important to stress that the burden of HIV disease on health delivery and financing systems greatly exceeds that of the AIDS cases that are reported as meeting CDC's surveillance case definition. Therefore, to the extent that the scope of this study is limited primarily to AIDS patients, the health delivery and financing problems identified in the five communities are likely to be understated.

Methodology

After reviewing the literature, we identified federal, state, and private organizations active in AIDS service delivery and financing programs and interviewed their representatives about community-based AIDS services and potential data sources.

We selected a judgmental sample of cities (defined by city or county limits or both to coincide with the service areas of local public health departments) to provide a wide range of observations representative of diverse situations. From CDC's list of the top 20 cities ranked by absolute number of cases, we eliminated the four with the largest AIDS caseloads, then picked communities ranging from relatively large caseloads (Philadelphia) to the smaller caseloads of Seattle, Baltimore, and New Orleans.[11] New Haven, which is not one of the top 20 cities, was selected because it is a much smaller city, and the majority of its cases are related to IV drug use. We included in our sample two communities with RWJF projects (New Orleans and Seattle-King County), one with a Health Resources and Services Administration (HRSA) project (Seattle-King County), and three others without supplemental funding (New Haven, Baltimore, and Philadelphia).

We collected general and demographic information on the five communities from available sources. Detailed data on community AIDS populations were obtained from the CDC AIDS surveillance systems in the state health departments. National AIDS service directories provided initial lists of contacts in each community.

During field work, we spent 2 to 3 weeks on site interviewing key state and local officials involved in the development and delivery of services to people with AIDS. These respondents included representatives of state health department AIDS offices and Medicaid programs; city or county health department AIDS officials; spokespersons for leading hospitals and clinics; physicians caring for people with AIDS; officials responsible for special projects, such as RWJF and HRSA demonstrations; staff at community-based AIDS voluntary organizations; and representatives of AIDS advocacy groups.

We obtained professional assessments about the availability and adequacy of a comprehensive range of inpatient and nonhospital services that AIDS patients need, and we corroborated and expanded upon interview information by reviewing available documents. Through content

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[11] See figure 2.1 for a map locating the five communities we reviewed and the 20 U.S. cities defined by CDC as metropolitan areas with the largest AIDS caseloads.

analysis of the in-depth interviews and supporting documents we (1) drafted summaries on the basis of the consensus of these local and state respondents and (2) sought comments on these drafts from key participants in the communities, incorporating their views as appropriate.

From the outset, we recognized that the quality and consistency of available data among our five communities would be uneven, especially on sources of payment and costs and charges for AIDS services. Because data on local service capacity and AIDS patient service utilization did not exist by type of service, we developed an inventory of AIDS services and sought informed judgments about the availability and adequacy of these services as well as sources of payment. The often limited nature of available data notwithstanding, the information presented here provides a broader base from which expansion of the general level of knowledge can proceed.

We conducted our review between January 1988 and March 1989 in accordance with generally accepted government auditing standards.

Chapter 2

AIDS Populations and Community Health Responses Varied

AIDS statistics aggregated across the United States tend to mask the range of differences among AIDS populations in particular communities, and thus do not reflect the nature and extent of local problems. AIDS population characteristics, as well as the number and impact of AIDS cases, varied significantly in New Haven, Philadelphia, Baltimore, New Orleans, and Seattle-King County, although AIDS caseloads were increasing rapidly in all five areas. The most striking differences were in the racial distribution of cases and the percent caused by IV drug use.

The five communities we reviewed also differed in their general populations and health resources. These differences, along with the unique characteristics of local AIDS caseloads, appear to have influenced the ways communities developed and provided services for people with AIDS.

General Population Characteristics

Figure 2.1 shows the geographic dispersion of the five communities we studied as well as the locations of the 20 cities with the largest reported AIDS caseloads in summer 1988. Total population size in the five communities ranged from about 124,000 people in New Haven to 1.6 million in Philadelphia.

As indicated in table 2.1, there are significant differences among the five communities in terms of racial mix and median income. Seattle-King County most nearly resembled the U.S. population in racial distribution, but differed strikingly from the other communities. Baltimore and Philadelphia had the largest proportions of black residents, while New Haven had the largest concentration of Hispanics. Moreover, median per capita income in 1983 was lower than the U.S. average in all communities we reviewed except Seattle-King County.

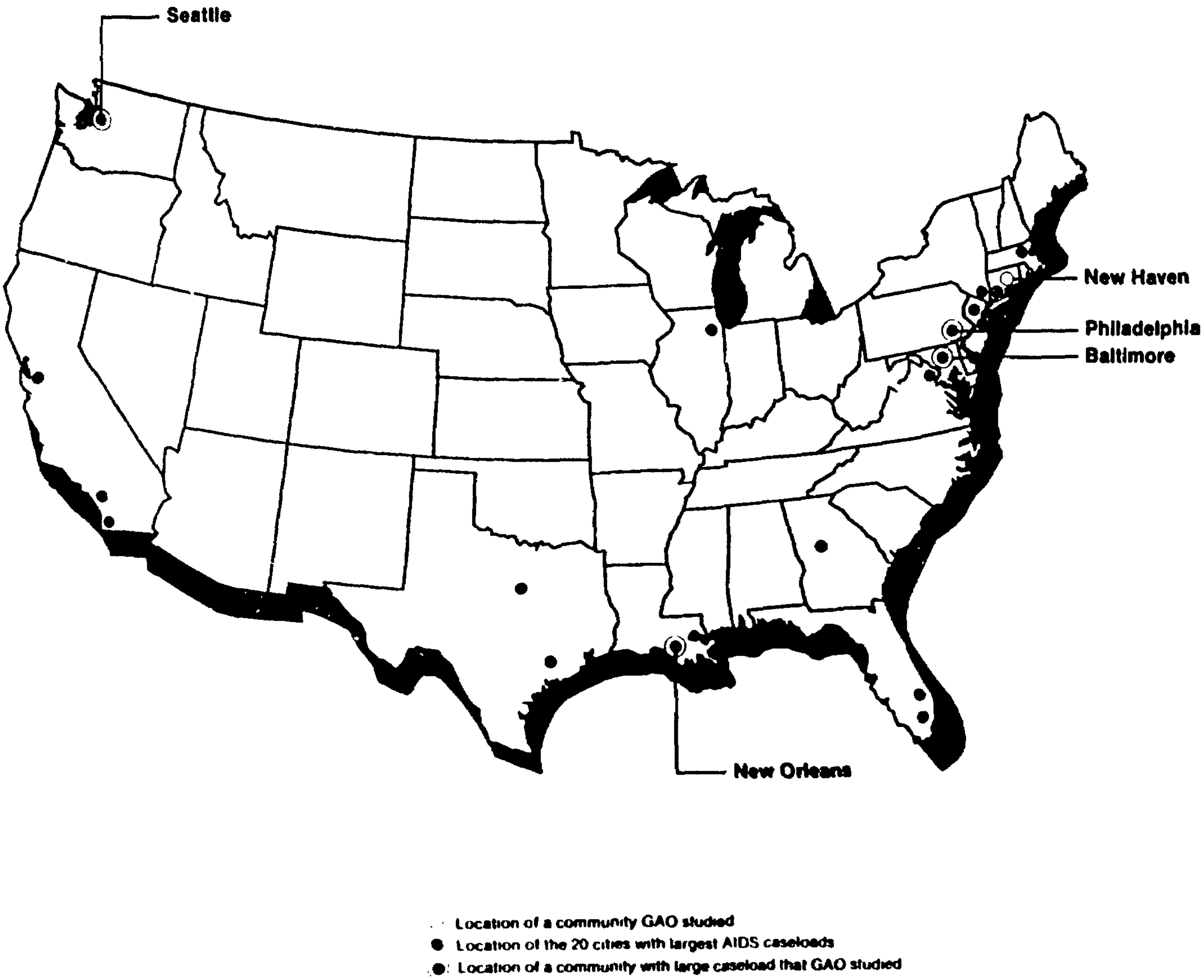
Table 2.1: Selected Population Indicators in Five Communities (June 1988)

General population indicators	New Haven	Philadelphia	Baltimore	New Orleans	Seattle-King County	United States
Population (1984)	124,188	1,646,713	763,570	1,318,759	1,323,950	236,495,000
Racial distribution (1980)[a]						
White	63%	58%	44%	65%	88%	83%
Black	32%	38%	55%	33%	4%	12%
Spanish	8%	4%	1%	4%	2%	6%
Median per capita income (1983)	$8,071	$7,870	$7,673	$9,245	$11,878	$9,496

[a] Racial distributions do not total 100 percent because the 1980 census defines "Spanish" as persons of Spanish origin who may be of any race.

Source: Bureau of the Census, State and Metropolitan Area Data Book 1986. New Orleans general population data are for the metropolitan area for comparability with AIDS population data reported in table 2.3.

Figure 2.1: Five Study Communities and 20 Cities With Largest AIDS Caseloads (June 1988)



Note San Juan, Puerto Rico, had the 18th largest AIDS caseload

Community Health Resources

Selected health resource indicators (see table 2.2) describe the supply of physicians as well as hospital and nursing home occupancy in the five communities. Hospital occupancy rates in the communities were as high or higher than the national average of 64 percent. Occupancy rates in community nursing homes ranged from just below the national average of 91 percent to a high of 97 percent, suggesting limited access for new admissions.

Table 2.2: Selected Health Resource Indicators in Five Communities (June 1988)

Health resource indicators	New Haven	Philadelphia	Baltimore	New Orleans	Seattle-King County	United States
Physicians per 100,000 population (1986)	312	330	534	398	298	184
Hospital occupancy rate (1986)	78%	74%	74%	64%	67%	64%
Nursing home occupancy rate (1982)	97%	92%	96%	97%	89%	91%

Sources American Medical Association, *Physician Characteristics and Distribution in the United States*, 1987 edition American Hospital Association, *Hospital Statistics*, 1987 edition, and Bureau of the Census *State and Metropolitan Area Data Book 1986*

Characteristics of Community AIDS Populations

Table 2.3 shows selected AIDS population characteristics in the five communities as of June 1988. The table indicates that national AIDS population statistics from the Centers for Disease Control (CDC) AIDS surveillance system do not reflect demographics and predominant means of HIV transmission in the five communities we reviewed. In fact, some communities differed strikingly from the national picture. For example, the proportion of IV drug-related AIDS cases ranged from 55 percent in New Haven to 2 percent in Seattle, compared with a national average of 19 percent in June 1988. Nationwide, 81 percent of AIDS cases in IV drug users were in minorities, compared with 41 percent of all AIDS cases in minorities. But in Philadelphia, although more than one-half of the AIDS cases were in minorities, the leading means of transmission was homosexual contact rather than IV drug use. (See app. I for more information on the unique characteristics of AIDS populations in the five communities.)

Table 2.3: Selected AIDS Population Characteristics in Five Communities (June 1988)

Size of AIDS population	New Haven	Philadelphia	Baltimore	New Orleans	Seattle-King County	United States
AIDS cases reported (cumulative to June 1988)	176	938	535	602	710	65,780
Cumulative AIDS cases per 100,000 population	142	57	70	46	54	28
AIDS population characteristics						
Race						
White (not Hispanic)	20%	41%	32%	67%	92%	59%
Black (not Hispanic)	65%	52%	67%	30%	5%	26%
Hispanic	14%	6%	2%	3%	2%	15%
Other	1%	[a]	[a]	[a]	1%	[a]
Sex						
Male	73%	94%	87%	95%	98%	91%
Female	27%	6%	13%	5%	2%	9%
Pediatric cases[b]	6%	1%	3%	1%	[a]	2%
Transmission category						
Homosexual/bisexual	25%	75%	61%	76%	84%	63%
IV drug user	55%	9%	23%	5%	2%	19%
Homosexual/bisexual and IV drug user	5%	9%	6%	9%	10%	7%
Heterosexual	11%	2%	5%	2%	1%	4%
Other or undetermined	3%	5%	4%	8%	3%	7%

[a] Indicates less than 1 percent

[b] Children younger than 13 years old

Sources AIDS case data from reports to CDC AIDS surveillance system by city and state health departments in Connecticut Pennsylvania, Maryland, Louisiana and Washington Note that New Orleans AIDS population data are for the metropolitan area because they were not available separately for the city U.S. data are from CDC's AIDS Weekly Surveillance Report United States, June 27, 1988 Percents may not add to 100 due to rounding

Total cumulative numbers of reported AIDS cases doubled nearly every year through 1987 in the communities we reviewed (see fig. 2.2). In June 1988, total reported cases ranged from 176 in New Haven to 938 in Philadelphia.[3] As measured by cumulative cases per 100,000 population, however, New Haven's rate of 142 cases per 100,000 population greatly exceeded the impact in the other communities. In all five communities, cumulative cases per 100,000 population exceeded the average 28 cases per 100,000 in the U.S. population.

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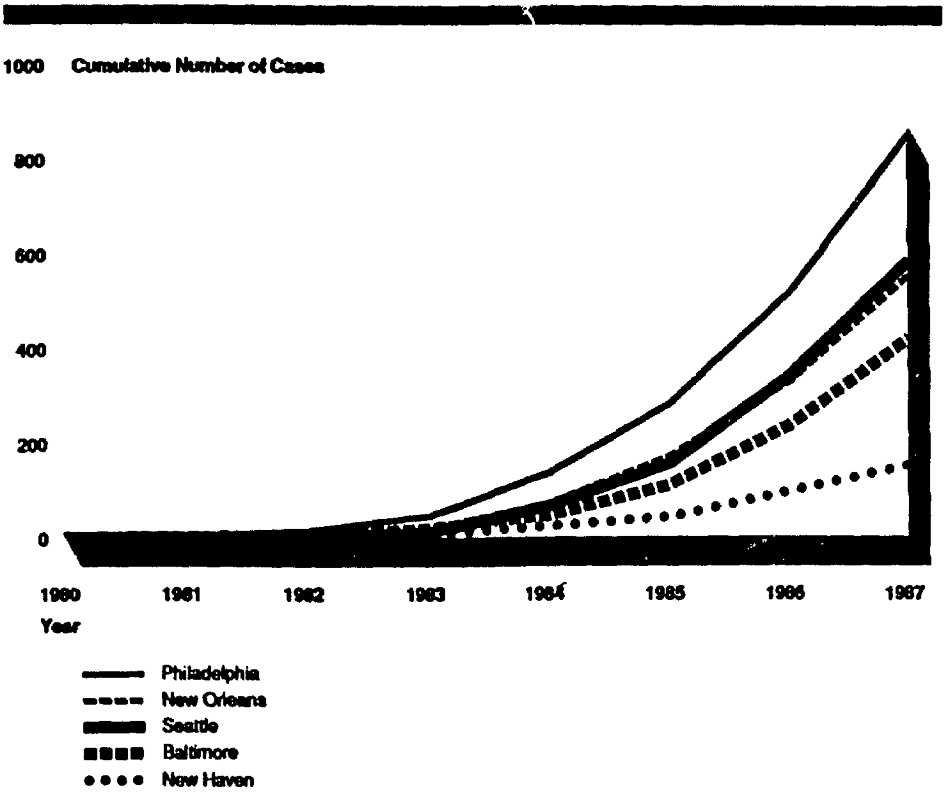
[3] CDC does not publish detailed AIDS population data at the community level, but we obtained data for the communities we reviewed from state surveillance offices that report to CDC. In these communities, hospitals and physicians report to the state authorities those cases of HIV infection that meet the CDC surveillance definition of AIDS. In turn, the authorities report these cases to CDC where they are aggregated at the state and national levels and published monthly

Figure 2.2: Growth in Cumulative Total AIDS Cases Reported in Five Communities (1981-87)



Source: Reports to CDC AIDS surveillance system by city and state health departments in Connecticut, Pennsylvania, Maryland, Louisiana, and Washington

In planning for the delivery of health services, however, estimated numbers of living AIDS patients are needed. According to CDC's surveillance system, over 57 percent of people with AIDS nationwide have died. AIDS mortality rates in the communities we reviewed somewhat exceeded the national rate, and were highest in Philadelphia, Baltimore, and New Haven at about 65 percent. In June 1988, reported numbers of people living with AIDS ranged from about 60 in New Haven to over 320 in Philadelphia. At the same time, approximately 6,500 people were living with AIDS in New York City and 2,500 were living in San Francisco.

By June 1989, nearly 100,000 AIDS cases had been reported nationwide.[2] From June 1988 to June 1989, the number of people living with AIDS rose from about 29,000 to more than 40,000. In our review, cumulative reported cases increased most rapidly over the past year in Philadelphia, from 938 to 1,389 cases; and growth was slowest in Seattle-King County, up from 710 to 951 cases in June 1989. Also last year, the composition of community AIDS caseloads by sex and race appeared generally stable. Between June 1988 and June 1989, however, the percent of cumulative AIDS cases caused by IV drug use rose from 9 to 12 percent in Philadelphia and from 23 to 28 percent in Baltimore. New Haven continued to report about 55 percent of its cases transmitted through IV drug use.

In summary, we found significant differences in the five community AIDS populations that can be expected to affect health service needs and community response. The problems of providing services to black and Hispanic drug users with AIDS in New Haven and, to a lesser extent, in Baltimore are quite different from those of serving white, homosexual men in Seattle and New Orleans. And because of IV drug-related cases, New Haven and Baltimore also have more women and children with AIDS than the other communities we reviewed. HIV-infected children, in particular, require a broad range of specialized medical and social support services.

Community Reactions to AIDS Varied

Underlying differences in demographics and health resources influenced when and how the five communities began to develop needed AIDS services. Although all five communities reported their first AIDS cases in 1981 or 1982, we found variations in the timing of actions by community organizations, medical providers, and local and state governments. The degree of cooperation and coordination among those responding to the epidemic also varied and, in Seattle and New Orleans, was augmented by demonstration grants.

Health experts believe additional research needs to be conducted on how to organize and deliver health services to people with AIDS. Community demonstration projects and health services research can identify cost-

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[2] People with AIDS are counted in the surveillance system if their condition meets the CDC definition of AIDS. Many others have debilitating and sometimes fatal HIV infections that do not, however, meet the surveillance definition. GAO reported that underreporting of both CDC-defined AIDS and other fatal HIV-related diseases understates the epidemic by as much as 50 percent. (AIDS Forecasting: Undercount and Lack of Key Data Weaken Existing Estimates, GAO/PEMD-89-13, June 1, 1989.) In addition, many others are infected with HIV but have not yet developed any symptoms of disease.

effective approaches to AIDS service delivery that are targeted to different AIDS populations, and help answer questions about the types of services most appropriate for AIDS patients. In the five communities we reviewed, for example, opinions differed on the appropriateness of traditional nursing home care and hospice services for AIDS patients. We believe that sponsoring research initiatives and disseminating findings on these subjects would help communities provide better care to AIDS patients by improving the planning and development of AIDS services.

The experiences of San Francisco and New York City are well-known, but they may not be applicable to communities in the second wave of the epidemic. San Francisco is recognized nationwide for its success in developing appropriate AIDS services while minimizing expenditures. The city's success is a result of coordinated public and private support and extensive volunteer services for its predominantly homosexual AIDS population. In New York City, on the other hand, developing community support and volunteer services for its large IV drug-related and minority AIDS caseload has been difficult.[3] AIDS care, therefore, has remained more heavily hospital-based and costly in New York. The five communities we reviewed reflect the diversity of U.S. communities in the second wave of the AIDS epidemic as well as how they are responding to the needs of people with HIV infection and AIDS.

Efforts of Volunteers, Providers, and Governments Varied

In all five communities, most of the first AIDS cases were diagnosed in homosexual men, whose community-based health and advocacy organizations initiated many of the early community responses to AIDS in 1982 and 1983. For example, Seattle's Northwest AIDS Foundation was a major contributor to AIDS services, providing an estimated 70,000 hours of volunteer effort in 1987. In New Orleans, a gay community organization spearheaded the response to AIDS. The Health Education Resource Organization (HERO), the leading voluntary AIDS organization in Baltimore, broadened its scope by developing an outreach program to educate IV drug users about AIDS.

Volunteer support, however, may diminish in the future as AIDS spreads beyond the homosexual community to include more IV drug users. The original gay AIDS organizations in Seattle, New Orleans, and Baltimore have expanded their programs to serve minorities, drug users, and

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[3] Arno and Hughes as cited in A.E. Benjamin, Philip R. Lee, and Sharon N. Solkowitz, "Case Management of Persons with Acquired Immunodeficiency Syndrome in San Francisco," Health Care Financing Review, annual supplement (1988), pp. 69-74.

women. The gay organization, AIDS Project New Haven, tried to expand its programs to the city's minorities, but had mixed success. A city AIDS Task Force formed in 1986, and eventually established separate programs for blacks, Hispanics, and women. The leading gay AIDS organization in Philadelphia split in 1986 to form separate organizations for homosexuals and minorities. Public and private officials in Philadelphia agreed that the response to AIDS has been slow, due to a lack of leadership and negative community attitudes about homosexuality.

When community-based AIDS volunteer groups were getting started in 1983, local medical providers in New Haven, Baltimore, and Seattle also began to develop AIDS care programs. In most cities, however, only a few health service providers have been active in caring for persons with AIDS. This has resulted in the lack of some types of services, notably nursing home care, and an inadequate supply of other services that is exacerbated by increasing AIDS caseloads.

The numbers and types of hospitals that provided inpatient AIDS care also varied in the five communities. The public hospitals in New Orleans and Seattle-King County have been important providers of AIDS inpatient services. In Philadelphia, a city without a public hospital, none of the hospitals developed a comprehensive, organized AIDS care program; but in New Haven and Baltimore, the teaching institutions developed comprehensive AIDS care programs.

There were differences in the timing of local government responses to AIDS in the five communities. For instance, in Seattle-King County, where there was an extremely homogeneous AIDS population and a history of cooperation between the gay community and city government, local funding initiated an AIDS program in the public health department in 1983. In Philadelphia, on the other hand, the city did not commit substantial funds for AIDS service development until July 1987.

State governments for the five communities we reviewed generally became involved in AIDS service delivery later than private organizations and local governments. A recent national survey of state-only spending on AIDS (excluding Medicaid, public hospitals, state-only indigent care programs, and support for city and county health departments), however, shows steady growth in state support to more than $156 million in 1988.[1] According to the same survey, states are spending an increasing

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[1] Rowe, Mona J., and Catlin C. Ryan, "Comparing State-Only Expenditures for AIDS," American Journal of Public Health, Vol. 78, No. 4 (Apr. 1988), pp. 424-429.

share of general revenues on AIDS patient care and support services, relative to AIDS education and prevention.

AIDS Demonstration Projects Helped Two Communities

In summer 1988, only two of the five communities we reviewed—New Orleans and Seattle—had outside funding to help coordinate available health resources in developing AIDS service systems. Both communities received Robert Wood Johnson Foundation (RWJF) project grants in 1986. In 1987, Seattle-King County also won supplementary funding for 3 years from the federal AIDS Service Demonstration Program in the Health Resources and Services Administration (HRSA).[5]

Although the Seattle-King County area's AIDS services were considered well-organized before its HRSA and RWJF awards, New Orleans officials told us that the RWJF grant was crucial to the development of an AIDS care network in that city, where local and state governments did not fund AIDS programs. AIDS services were organized around the grant-funded AIDS outpatient clinic through cooperative arrangements and contracts with other providers. Officials in other cities told us that the lack of special project funding slowed the development of coordinating mechanisms.

RWJF provided the first substantial funding for AIDS service demonstration projects in 1986.[6] The nine 4-year AIDS service demonstrations,

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[5] As demonstration programs, both the RWJF and HRSA AIDS service programs had specific demonstration objectives and limited available funding levels. The nine RWJF grants were awarded to communities whose applications documented organized local support, a commitment to future funding, and likely success in implementing a continuum of services and case management. HRSA awarded its first four grants to the cities most affected by AIDS (New York, San Francisco, Los Angeles, and Miami), and then considered applications only from a list of large metropolitan areas. New Haven, for example, was too small an area to apply for an HRSA grant regardless of its need for assistance. Independent evaluations of the AIDS demonstration programs are underway. The RWJF projects are being evaluated by researchers at Brown University, and the four largest HRSA demonstrations are being evaluated by Systemetrics and Project Hope.

[6] In 1986, RWJF funded AIDS service demonstration projects in Atlanta; Dallas; New York City; Palm Beach and Dade County, Florida; Nassau County, New York; the state of New Jersey; New Orleans; and Seattle-King County.

modeled on the San Francisco AIDS service system, were designed to support community coalition-building and promote case management and home and community-based care.[7]

HRSA has awarded about $60 million for community AIDS services,[8] including (1) service demonstration grants to 21 metropolitan areas with the largest AIDS caseloads in fiscal years 1986 through 1988, (2) additional demonstration projects in fiscal year 1989 and a new program to assist low-incidence cities and states in planning AIDS services, and (3) projects to renovate and construct long-term care facilities for people with AIDS.

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[7] Neither Baltimore nor Philadelphia had obtained RWJF or HRSA adult AIDS demonstrations by summer 1988. Philadelphia was the only major city that did not apply for HRSA funding in 1987, but it did win funding in September 1988. The Pew Charitable Trusts provided $250,000 for the Philadelphia Commission on AIDS (September 1987 through October 1988), which sponsored AIDS education activities for community business and church groups, as well as local AIDS research, needs assessment, and planning. New Haven did not obtain outside AIDS funding until late 1988, when the city was awarded a National Institute on Drug Abuse AIDS outreach project and an RWJF special project grant for 1989.

[8] HRSA funding for AIDS patient care has been included in the PHS budget. Specifically, patient care services accounted for only 5 percent of the $1.3 billion fiscal year 1989 PHS AIDS budget. In contrast, about 45 percent of the PHS budget was allocated for biomedical research and 49 percent was for epidemiology and public health control measures.

Chapter 3

Community AIDS Service Systems: Gaps in Services Prevail

At their current AIDS caseloads, the five communities we reviewed were experiencing demands for AIDS services that frequently exceeded existing delivery capacity. Some outpatient health and support services, especially, were in very limited supply. And CDC's recommendation that people testing HIV positive be monitored and treated preventively could greatly increase demand for outpatient services. Because AIDS caseloads are nearly doubling every year, current service delivery problems will likely be more severe in the future.

Despite variations in community response and differences among local AIDS populations, officials and health providers in the five communities reported that as of summer 1988, inpatient services were generally available for adult and pediatric AIDS patients. Relatively few hospitals and physicians, however, were providing AIDS services. This resulted in strains on capacity in some communities as AIDS caseloads increased.

Long-term care and support services for people with AIDS—especially nursing home, hospice care, mental health services, home health, and housing itself—were difficult to develop in the communities we reviewed. In particular, the health services most needed to support patients in nonhospital settings and at home were missing, very limited, or nearing or exceeding capacity. Consequently, AIDS patients, especially those without private insurance, either were not always able to obtain needed services in the most appropriate settings or they faced waiting lists. Coordinating health and social services was especially difficult when entire families had HIV infection as the result of IV drug use and heterosexual or mother-to-child transmission.[1]

Availability of AIDS Services Varied, but Gaps Remained in All Communities

We asked key health officials and providers in each of the five communities what in their judgments were their most critical AIDS service needs. In approximate order of importance, they reported the service gaps listed in table 3.1—housing options, home health nursing and attendant care, mental health services, nursing home services, dental care, drug abuse treatment, hospice, and case management services. Other services, although available, were cited as needs due to limited supply.

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[1] See Pediatric AIDS: Health and Social Service Needs of Infants and Children (GAO/HRD-89-96, May 5, 1989).

Table 3.1: Most Critical AIDS Service Needs Reported in Five Communities (Summer 1988)

	New Haven	Philadelphia	Baltimore	New Orleans	Seattle-King County
Most critical needs	Substance abuse treatment (methadone slots)	Adult housing options	Dental care	Nursing home care	Mental health services
		Hospice care	Home attendant care	Home attendant care	Home attendant care
	Adult housing options	Dental care			
	Nursing home care				
Important needs	Case management	Home nursing and attendant care	Home nursing care	Adult housing options	Adult housing options
		Mental health services	Hospice care	Dental care	Substance abuse treatment
				AZT	
			Mental health services		Nursing home care
Other needs	Dental care	Nursing home care	Nursing home care	Mental health services	Outpatient medical care
	Home attendant care	Outpatient medical care	Outpatient medical care	Substance abuse treatment	Social work
	Hospice care				
	Mental health services	Substance abuse treatment	Case management	Outpatient medical care	
	Social work	Case management	Adult housing options	Case management	
		Pediatric foster care	Substance abuse treatment	Social work	

Although the specific gaps and shortages varied with the community, the continuum of health services needed by people with AIDS was incomplete in all five of the communities we reviewed. The gaps were attributed to a combination of factors, including reluctance of some providers to serve AIDS patients, inadequate capacity, low reimbursement rates, inability to pay on the part of patients, and regulations that impeded access. When a full range of home and community-based services was not available, appropriate referrals could not be made to less intensive and less costly levels of care, and community volunteer services were not always able to fill the gaps.

Service delivery problems, such as those reported in communities we reviewed, will likely worsen as AIDS caseloads increase. We describe below how the communities provided some of the services required for people with AIDS.

Inpatient Services Available but Reaching Capacity

Inpatient hospital services were available for adults and children with AIDS in all five communities, although in some communities increasing AIDS caseloads were filling available capacity (see table 3.2). None of the communities we reviewed, however, had a general shortage of inpatient beds, such as has developed in New York City.

Table 3.2: Availability of Inpatient Services for People With AIDS in Five Communities (Summer 1988)

	Available	Available but reaching capacity	Available but limited capacity	Not available
New Haven				
Inpatient services for adults	●			
Inpatient services for children	●			
Public hospital				●
Philadelphia				
Inpatient services for adults	●			
Inpatient services for children	●			
Public hospital				●
Baltimore				
Inpatient services for adults		●		
Inpatient services for children	●			
Public hospital				●
New Orleans				
Inpatient services for adults	●			
Inpatient services for children	●			
Public hospital	●			
Seattle-King County				
Inpatient services for adults	●			
Inpatient services for children	●			
Public hospital	●			

In the communities we reviewed, the hospitals that cared for AIDS patients early in the epidemic have seen their caseloads grow rapidly. Inpatient services have tended to develop in a few hospitals and remain concentrated there as other physicians and hospitals refer their AIDS patients and patients themselves seek out the most experienced programs. Integrating or mainstreaming AIDS patients—that is, caring for them in existing facilities and programs along with other patients—was promoted in the states of Maryland and Washington. A larger number of hospitals in each community needs to become active in AIDS care in order to keep up with the increasing demand.

In two hospitals with designated AIDS inpatient units, caseloads sometimes exceeded unit capacity. The 9-bed designated AIDS unit at Johns Hopkins Hospital in Baltimore was often full in summer 1988, resulting in AIDS patients being treated elsewhere in the hospital.[2] Charity Hospital of New Orleans operated an inpatient unit with about 25 beds, but capacity varied with staffing levels. As a public hospital, Charity has been under state budgetary restrictions for at least 2 years. It served an average 12 to 20 AIDS patients a day.

According to many officials we interviewed, inpatient care was available to AIDS patients regardless of their insurance coverage or ability to pay. Those who were uninsured or on Medicaid, however, were more likely to use public hospitals or hospitals affiliated with university medical schools. In the two communities with public hospitals, those hospitals were providing substantial AIDS care. In New Orleans, for example, AIDS patients with private insurance were admitted to private hospitals; those without private insurance were much more likely to be treated in Charity Hospital, which provided three times the volume of AIDS inpatient care of any private hospital in the city. Seattle-King County also had a public hospital, which was one of the area's three leading hospitals caring for AIDS patients.

In Philadelphia, private pay AIDS patients used a number of private hospitals, while Medicaid patients primarily used Temple University Hospital and Giuffre Medical Center. Yale-New Haven Hospital's comprehensive AIDS care program was the leading provider of inpatient care in that city, regardless of patient source of payment. Likewise, in Baltimore, Johns Hopkins Hospital and the University of Maryland Hospital treated nearly all AIDS patients, both paying and nonpaying.

Inpatient pediatric AIDS care was available in all five communities. Although long inpatient stays were reported for a few babies in Baltimore, none of the communities reported a problem such as exists in the New York City area, where babies have lived in hospitals for extended periods of time when no foster homes could be found for them. With the exception of New Haven and Baltimore, the communities had relatively few reported cases of pediatric AIDS. Numbers of cases meeting CDC's reporting definition, however, may understate the need for pediatric AIDS services, according to public health officials in some communities.

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[2] Johns Hopkins Hospital expanded its designated AIDS inpatient unit to 15 beds in December 1988, and planned another expansion to 21 beds in spring 1989.

Outpatient Medical Services and AZT Available, but Dental Care Limited

People with AIDS in the five communities could usually obtain outpatient medical care in a variety of settings, as well as the expensive prescription drug azidothymidine or zidovudine (AZT). Dental care, however, was not generally available and was considered a critical need in two communities (see table 3.3).

Table 3.3: Availability of Outpatient Services for People With AIDS in Five Communities (Summer 1988)

	Available	Available but reaching capacity	Available but limited capacity	Not available
New Haven				
Outpatient services	•			
AZT	•			
Dental Services			•	
Philadelphia				
Outpatient services			•	
AZT	•			
Dental services				X[a]
Baltimore				
Outpatient services			•	
AZT	•			
Dental services				X[a]
New Orleans				
Outpatient services		•		
AZT			•[b]	
Dental services			•	
Seattle-King County				
Outpatient services		•		
AZT	•			
Dental services	•			

[a] Respondents reported critical need for services

[b] Availability limited by payment problems

Outpatient Care

Outpatient medical care for people with AIDS includes general physician services, health monitoring, and ambulatory medications, among other services. This care may be provided in hospital-based AIDS clinics, hospital general outpatient departments, public and private freestanding AIDS clinics, community health centers, and private physician offices. In four communities, outpatient medical resources were reported to be available but at or reaching capacity. Often only a few physicians and facilities cared for the majority of AIDS and HIV cases. Moreover, according to officials in the communities, services were not always well-coordinated to assure, for instance, that IV drug users, minorities, and the poor were referred for other needed services.

AIDS outpatient medical clinics, which may monitor and treat people in all stages of HIV infection,[3] were heavily used. For example, all three centers for outpatient AIDS services in Baltimore—two university hospital-based AIDS clinics and a freestanding clinic—were reported to be at capacity, with waiting lists for new patients. Hospital officials said low Maryland Medicaid reimbursement rates made it difficult to expand their outpatient AIDS services, and the University of Maryland was limiting new admissions to its outpatient clinic.

More outpatient medical services were needed for people with AIDS and HIV infection in Philadelphia. None of the leading hospitals had an organized AIDS outpatient program. AIDS patients were treated in general outpatient departments and by a few private physicians. City health department clinics and federally supported community health centers provided primary care for low-income people, but only one community health center in Philadelphia offered specialized services for AIDS and HIV patients

Outpatient AIDS services were available but reaching capacity in Seattle. The city's community clinic system was a primary care resource for low-income and uninsured people, including those with HIV infection and AIDS, who received specialized care in three of the clinics. In New Orleans, the largest outpatient care center (the C-100 AIDS Clinic at Charity Hospital, which was supported by state and Robert Wood Johnson Foundation grant funds) had a 3- to 4-week wait for new admissions.

The national community health centers program, administered by the Health Resources and Services Administration (HRSA), currently provides primary care services for the poor. To a significant extent, the populations these centers serve include low-income people with AIDS as well as those at risk of HIV infection. In New Haven, in addition to hospital-based outpatient care, two community health centers offered primary care services to predominantly low-income, minority, and medically underserved neighborhoods. One of the centers provided health services and AIDS education to people with AIDS and those at risk for HIV infection, who were mostly minorities, women, and IV drug users, often homeless.

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[3] CDC's recommendation in June 1989—that all persons who test HIV positive be monitored on an outpatient basis—could bring a flood of new patients to AIDS clinics and physicians.

AZT

AZT is the only antiviral drug that has been shown to prolong the survival of people with AIDS. It was available in the five communities with relatively few limitations, considering the high per patient annual costs of the drug—$8,000 to $10,000.[4] AIDS patients, private health insurance, state Medicaid and other state assistance programs, and a special federal allocation paid for the drug.

In 1987, the federal government provided $30 million to help states purchase AZT for AIDS patients who lacked insurance or private means to pay for it. This was an important source of funding for AZT in all communities, but especially in New Orleans, where AZT was not covered by the state Medicaid program until March 1988. Another important source of AZT in New Orleans has been the AIDS drug clinical trials program funded by the National Institutes of Health at Tulane and Louisiana State Universities.

State and local officials in Maryland expressed concern about special public payment for AZT and other AIDS therapeutic drugs. More drugs are likely to be approved for larger segments of the HIV-infected population, and the AZT payment precedent could portend substantial cost increases for AIDS care as well as raise questions about inequities in pharmaceutical coverage for patients with other illnesses. In June 1989, CDC recommended that, through blood tests, an HIV-infected person undergo immune system monitoring every 6 months; and if immune function falls below acceptable levels, the person should be given pentamidine to prevent pneumocystis carinii pneumonia. This level of care for asymptomatic people is likely to raise overall costs significantly.

Dental Services

Dental care for people with AIDS or HIV infection was difficult to obtain in all but one community. Yet it is an important service for persons with suppressed immune systems because infections affecting the mouth are common and can become serious.

Officials in Baltimore agreed that dental care was a major service gap, available only at the University of Maryland's dental school clinic or from a few private dentists. A similar situation was reported in Philadelphia. Access to dental services also was limited in New Haven and New Orleans. Reported barriers included inability of patients to pay,

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[4] AIDS patients are staying out of the hospital and living longer using AZT, but it is still unclear if the net effect of this expensive drug will be to increase or reduce total costs of care. A small study completed in December 1988 by Seitovsky and Cline indicates that AZT reduces overall costs of AIDS care during the first year after diagnosis.

lack of Medicaid dental coverage for beneficiaries over 18 years old, and the reluctance of dentists to treat people with AIDS.

Long-Term Care Services Difficult to Develop

All five of the communities we reviewed had problems providing long-term care services for people with AIDS, such as nursing home, hospice, and home health nursing and attendant care (see table 3.4). Early in the AIDS epidemic, AIDS patients most often were treated in research hospitals where they experienced intensive medical treatment and relatively long stays. Medical specialists now believe that hospital admissions, lengths of stay, and their associated costs can be greatly reduced by providing appropriate care in nonhospital settings. But it has been difficult in many communities to develop or gain access to some of these services.

Table 3.4: Availability of Long-Term Care Services for People With AIDS in Five Communities (Summer 1988)

	Available	Available but reaching capacity	Available but limited capacity	Not available
New Haven				
Nursing home				X[a]
Hospice			•	
Home health nursing	•			
Home attendant			•	
Philadelphia				
Nursing home			•	
Hospice			X[a]	
Home health nursing			•	
Home attendant				•
Baltimore				
Nursing home			•	
Hospice				•
Home health nursing			X[a]	
Home attendant				X[a]
New Orleans				
Nursing home				X[a]
Hospice	•[b]			
Home health nursing	•[b]			
Home attendant				X[a]
Seattle-King County				
Nursing home			•	
Hospice	•			
Home health nursing	•			
Home attendant			X[a]	

[a] Respondents reported critical need for services

[b] Supported with grant subsidy

Nursing Home Care

Some AIDS patients require additional nursing care and supervision following discharge from a hospital; nursing home beds may also be needed for patients whose debilitation or dementia precludes caring for them elsewhere. Nursing home care has not been available as an option for most AIDS patients, however, because very few homes admit persons with AIDS.

A commonly cited reason for not admitting AIDS patients is that many nursing homes do not meet state health department facility and staffing requirements for patients with infectious diseases. Some nursing home administrators say they are concerned that other residents and their families may object to admission of AIDS patients. Others contend that Medicaid reimbursement rates are too low for the higher level of care and infection control measures AIDS patients require. In many parts of the country, nursing home beds are in short supply in general, and homes have little incentive to admit AIDS patients.

On the other hand, some health providers and AIDS advocacy groups state that nursing home care is not always appropriate for many AIDS patients. The changeable medical conditions of AIDS patients require various types and intensities of health services, in contrast to the relatively stable, chronic conditions typically managed in nursing homes. Moreover, AIDS patients, most of whom are young men, often do not want to be treated in nursing homes.

In New Haven and New Orleans, no nursing homes accepted people with AIDS. In New Haven, the lack of nursing home care reportedly resulted in extended and costly hospital stays and, in some cases, discharges to shelters for the homeless, the YMCA, or the streets. Louisiana approved a posthospital acute care facility for people with AIDS in New Orleans, scheduled to open in 1989, with an increased Medicaid nursing home reimbursement rate.

In Philadelphia, 16 beds were available only for uninsured AIDS patients in one nursing home, which was publicly funded. Seattle officials said people with AIDS who needed nursing home care usually were able to get it and, in addition, a new residential care facility was planned to open in 1991. The Maryland state health department attempted to encourage nursing homes to admit people with AIDS by (1) offering expedited certification to admit infectious patients and (2) negotiating a substantially increased Medicaid reimbursement rate for HIV patients. Only one nursing home in Baltimore responded. It opened a new 20-bed unit for AIDS patients in April 1988, which has drawn patients from Maryland, Pennsylvania, Delaware, and Washington, D.C.

Hospice Care

Where it is available, hospice care can be helpful to people with AIDS in the terminal stage. Hospice programs are designed to provide palliative (pain control) and support services for the terminally ill, either in hospice facilities or through services to patients in their own homes.

Admission to hospice care generally requires that the patient is not expected to live more than a few months, which is not always clear with AIDS patients. In addition, the hospice patient usually must agree to forego aggressive medical treatment in exchange for hospice benefits.

These requirements are not suitable to many AIDS patients, both because (1) their conditions are unpredictably variable and (2) they need medical treatment for numerous and recurrent infections. Nonetheless, for reasons of quality of life as well as cost, hospice services for AIDS patients may be preferable to nursing home or hospital care during the terminal stage.

The RWJF AIDS project in New Orleans integrated home-based hospice services into the AIDS care network by using grant funds to subsidize care for AIDS patients without private insurance. In New Orleans, the hospice program made an exception for people with AIDS to the palliative-treatment-only regimen in order to fight infections with antibiotics.

Both facility-based and home hospice services were available to many AIDS patients in Seattle, and a hospice near New Haven reserved five beds for AIDS patients. Hospice services for people with AIDS were not available in Baltimore and were limited and reported to be a critical need in Philadelphia. None of the states that the five communities are in covered hospice care in its Medicaid program at the time of our review.

Home Health Nursing Services

Although many providers agree that nursing and support services for people with AIDS can be delivered appropriately in the patient's own home or in a group home, an adequate supply of home health nursing services was not available in all of the communities. Officials in some communities said many home health agencies believe Medicaid reimbursement is too low for AIDS patients, who generally require longer visits and hence are more costly than other home health clients.[5] When home health care is not available, people with AIDS may require institutional care, or their family, friends, and volunteers may care for them.

In Philadelphia, home health services were reported to be limited. Such care was generally not available because Pennsylvania Medicaid only covered up to 4 hours of home nursing care per week, and reimbursement was reported to be so low that some agencies would not accept Medicaid patients with AIDS. In other communities, some officials told us low reimbursement rates and eligibility requirements limited AIDS patients' access to home health nursing services. In New Orleans, RWJF grant funds were used to subsidize care.

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[5] Officials in Seattle-King County said Washington Medicaid bases its home nursing reimbursement rate on an average 45 to 50 minutes per visit, and because AIDS patients may require up to 90 minutes per visit some home health agencies are limiting the number of patients they will accept.

Specific problems can limit the use of home care benefits by Medicaid-eligible AIDS patients. For example, a University of Maryland Hospital official reported it takes 6 weeks to receive Medicaid home health benefits, and all forms must be redone after each hospitalization. In addition, Medicaid regulations require the home health patient to be homebound, which is unrealistic for the changing conditions of AIDS patients. Baltimore officials cited home health nursing as a critical service need.

Home Attendant and Chore Services

People with AIDS had more trouble obtaining home attendant services than medically oriented home nursing care. Officials in all five communities said more home attendant services to help with household and personal chores were needed so patients could remain at home and avoid institutional care.

In Baltimore, New Orleans, Philadelphia, and Seattle, home attendant care was cited as a major service need. Officials in Seattle, New Orleans, and Baltimore reported that volunteers recruited and trained by gay community organizations have contributed significantly to home support for AIDS patients. Many volunteer organizations told us they were concerned about their ability to meet increasing demand, however, and volunteer services have been especially difficult to develop for minority and IV drug-using AIDS patients.

One Maryland Medicaid initiative for AIDS was coverage for a more intensive level of personal care services—at least 16 hours daily of non-medical, home-based assistance and supervision. The new level of care became available in July 1988, but as of December 1988, no private agencies offered the service.

Essential Support Services Limited

Support services that people with AIDS need, such as medical case management, social work services, mental health and psychiatric services, foster care, and substance abuse treatment, were difficult to obtain in many of the communities we reviewed (see table 3.5). In most cases, services were available to some patients but limited service capacity was a problem.

Table 3.5: Availability of Support Services for People With AIDS in Five Communities (Summer 1988)

	Available	Available but reaching capacity	Available but limited capacity	Not available
New Haven				
Case management				•
Social work			•	
Mental health			•	
Pediatric foster care	•			
Substance abuse treatment			X[a]	
Philadelphia				
Case management			•	
Social work			•	
Mental health			X[a]	
Pediatric foster care			•	
Substance abuse treatment			•[b]	
Baltimore				
Case management			•[c]	
Social work			•	
Mental health			X[a]	
Pediatric foster care			•	
Substance abuse treatment			•[b]	
New Orleans				
Case management		•[d]		
Social work		•[d]		
Mental health			•	
Pediatric foster care	•[e]			
Substance abuse treatment			•[b]	
Seattle-King County				
Case management	•[d]			
Social work		•[d]		
Mental health			X[a]	
Pediatric foster care	•[e]			
Substance abuse treatment			•[b]	

[a] Respondents reported critical need for services.

[b] Capacity for methadone currently adequate.

[c] New program summer 1988.

[d] Supported with grant subsidy.

[e] Few pediatric cases.

Medical Case Management

Medical case management is recommended as an important component of service delivery for people with AIDS as well as other high-cost acute and chronic diseases.[6] AIDS patients may be particularly good candidates for case management because treatment is costly and the course of the disease is likely to be unpredictable. They may require a wide range of support services. Access to nonhospital services is emphasized to ensure that each patient is appropriately cared for in the least intensive and presumably least costly setting, although cost savings due to case management for AIDS patients have yet to be established through research.[7]

The availability of case management services, however, was very limited for people with AIDS in New Haven and Philadelphia in summer 1988. In Baltimore, case management was just becoming available to Medicaid recipients with AIDS. In New Orleans and Seattle, case management was available and supported in part by special AIDS project funding.

Both the RWJF and HRSA AIDS demonstrations require case management components. Case managers in the RWJF-funded New Orleans AIDS Project, which provided case management for everyone using its services, were overloaded in summer 1988. In addition to the Northwest AIDS Foundation efforts, case management services in Seattle were provided by staff at the three hospital-based adult AIDS programs and at the children's orthopedic hospital with Medicaid coverage and other public and grant support.

State Medicaid programs may provide case management services to specific groups of recipients, such as people with AIDS or HIV infection. Washington obtained a Medicaid waiver in 1987 to provide case management services for people with AIDS. In fiscal year 1988, Louisiana Medicaid covered case management services, and Maryland and Pennsylvania added coverage in fiscal year 1989. Connecticut Medicaid did not cover case management.

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[6] The dual purpose of case management is to ensure access to appropriate services while controlling costs, principally by preventing unnecessary hospitalization. A case manager (usually a nurse) develops a comprehensive care plan for each person soon after he or she is diagnosed, and then helps the patient obtain the necessary services.

[7] Benjamin, Lee, and Solkowitz, "Case Management of Persons With Acquired Immunodeficiency Syndrome in San Francisco," Health Care Financing Review, annual supplement, (1988), pp.69-73. See also Health Insurance Association of America, "AIDS Case Management: What Health Insurance Companies Are Doing" (no publication date). Benjamin reported recently that case management for the elderly has resulted in improved quality of care, but no cost savings. No research specifically on AIDS case management has been completed, but experience with the elderly suggests caution in expectations for cost savings.

In addition to covering case management for people with HIV infection under Medicaid, in summer 1988, Maryland was implementing a state-funded AIDS Diagnostic Evaluation Unit demonstration program that incorporated case management to help distribute the burden of AIDS care across more providers in the state. Two diagnostic evaluation units for HIV infection—one for adults at Johns Hopkins Hospital and one for children at the University of Maryland—were funded to serve as state referral centers. Physicians may refer HIV-infected patients to these units for thorough diagnosis, evaluation, and medical care plan development. Patients then are referred back to their community physicians or local case managers for monitoring. In addition to a few state-employed AIDS case managers, the state was contracting for case management services from community organizations such as the Health Education Resource Organization (HERO) in Baltimore.

Social Work Services

In all five communities, social work services were available to some people with AIDS. Social workers focus on (1) establishing eligibility for public or private payment for AIDS services; (2) planning services for patients discharged from the hospital; and (3) obtaining needed social support services, such as housing, income maintenance, and transportation. The services were most often provided by hospital-based social workers.

Officials in New Orleans and Seattle reported that social work services for people with AIDS were available, but reaching capacity. In New Haven, Philadelphia, and Baltimore, more capacity to deliver social work services was needed.

Mental Health Services

Mental health and psychiatric services were limited for people with AIDS in all five communities. In Philadelphia, Baltimore, and Seattle, the lack of mental health services for AIDS patients was cited as a major service gap. In Seattle, for example, Medicaid gave priority for psychiatric services to long-term chronic and severely mentally ill patients, which left little public assistance for the acute mental health problems often experienced by people with AIDS. Also, facilities for inpatient psychiatric care generally were not prepared to deal with both mental and physical health needs of AIDS patients.

Officials in New Haven, Baltimore, and New Orleans reported that mental health services were available to some patients, especially those who had private insurance; but inadequate capacity and inability to pay were barriers for many who needed the services. In most states, Medicaid mental health benefits were available primarily for inpatient psychiatric care. Community mental health centers serving low-income clients have limited resources and capacity to meet the needs of people with AIDS. AIDS voluntary organizations helped fill this gap by providing hotline and crisis intervention services and sponsoring volunteer buddies and AIDS self-help groups, but their resources too were limited.

Foster Care

Hospital-based pediatric AIDS programs reported that families with more than one HIV-infected member require extensive support services (e.g., income maintenance, housing, food) in addition to medical care. HIV-infected infants and children of such families may require foster home placement when their families are unable to care for them.

Philadelphia and Baltimore hospitals reported some HIV-infected babies needing foster placement, but not many infants remaining in the hospital because of a lack of discharge options. In New Haven, the city in our review with the most serious pediatric AIDS problem, officials reported that the state's foster placement program for children and youth had found homes for more than 30 pediatric patients with possible HIV infection by summer 1988. In Baltimore, the state foster care program placed about 50 HIV-infected children, but more homes were needed.

Foster children are covered by Medicaid in all states. In both Connecticut and Maryland, foster parents for HIV-infected children received extensive special training as well as support services for the children. Connecticut foster parents of HIV-infected infants received increased payments, and in Maryland, such foster parents received the highest rates paid by the state.

Substance Abuse Treatment Services

The chronic shortage of substance abuse treatment capacity across the nation has also affected AIDS services in the five communities we reviewed. New Haven was most severely affected, with more than one-half of its AIDS cases caused by IV drug use. Officials there agreed that the single most critical AIDS service need was for more methadone maintenance slots and other drug treatment programs.

Two large drug treatment programs in New Haven—one private and one state-supported—treated drug users with HIV infection and AIDS, but they did not offer drug treatment services specifically designed for HIV-infected clients. In summer 1988, outpatient methadone maintenance programs had waiting lists as long as 4 to 6 months for about 60 people. Not only was capacity inadequate, but officials said the programs needed to be more accessible to the largely minority populations at risk for AIDS. Although adolescent IV drug use is seen as a growing problem in New Haven, methadone maintenance programs were not open to this population.

In contrast to New Haven, Philadelphia reported that enough methadone maintenance slots were available for anyone seeking the treatment, including HIV-infected people. But it was reported that one-half of the IV drug use in Philadelphia's Latino community involved injecting cocaine, for which costly inpatient detoxification and drug-free programs are the accepted treatment. These options were not available for patients without private insurance, and the average wait for treatment was 2 to 4 months. There were no drug treatment programs in Philadelphia specifically for people with AIDS until September 1988, when the city opened a group home for IV drug users with AIDS.

In Baltimore, HERO operates a street outreach AIDS education and prevention program for IV drug users with city and state drug abuse administration funding. Baltimore has 10 city methadone clinics, and officials were trying to provide immediate access to methadone treatment slots and other drug programs for HIV-infected people. In New Orleans and Seattle, HIV infection rates in local IV drug populations were relatively low, but existing drug treatment programs were treating some people with HIV infection and AIDS. Officials in Seattle-King County reported that public assistance funds were not adequate to pay for drug treatment for low-income and indigent IV drug users.

In the communities we reviewed, services for people with HIV infection were not integrated well with existing substance abuse prevention and treatment programs. For example, New Haven's drug programs lacked adequate capacity for all non-AIDS drug users seeking treatment, and, consequently, the counseling and special services required for IV drug users with AIDS could not be effectively provided.

Difficulties in All Five Communities Providing Housing Assistance

The lack of suitable housing emerged as a significant problem for people with AIDS in the five communities we reviewed (see table 3.6). When AIDS patients become too ill to work or lose their jobs and incomes, many are at risk of losing their homes as well. Others may become homeless when landlords or family force them out because of their diagnosis. AIDS-related housing problems can be expected to worsen as more low-income IV drug users and minorities contract the disease.

Table 3.6: Availability of Housing Assistance for People With AIDS in Five Communities (Summer 1988)

	Available	Available but reaching capacity	Available but limited capacity	Not available
New Haven				
Housing assistance			X[a]	
Adult residential care				X[a]
Philadelphia				
Housing assistance			X[a]	
Adult residential care			X[a]	
Baltimore				
Housing assistance			•	
Adult residential care			•	
New Orleans				
Housing assistance			•	
Adult residential care			•	
Seattle-King County				
Housing assistance			•	
Adult residential care			•	

[a] Respondents reported critical need for services

The lack of housing hinders the delivery of some community-based services for people with AIDS and may result in unnecessary hospitalizations. Adult patients may require placement in group homes or financial or nursing assistance to remain in their own homes.

Adult residential options—primarily group homes—were cited as a critical service need in New Haven and Philadelphia. Housing for IV drug users with AIDS, many of whom are indigent, was an especially difficult problem in Philadelphia and New Haven. There was one group home for people with AIDS in New Orleans. Group homes were available to some people with AIDS in Baltimore and Seattle, but more homes were needed. AIDS patients in Baltimore also benefited from a state program called Project Home, which arranges foster homes for chronically disabled, homeless adults. Three to six people may be placed in each certified foster home, and their care is paid by their disability checks and state subsidies.

Some general housing assistance, such as rent subsidies and vouchers for access to public housing, was available to low-income people with AIDS in Seattle and Baltimore, but little or nothing was available in the other communities.

Summary

Our review of the availability of AIDS services in five communities found that despite efforts to develop and deliver services significant gaps remained. Communities faced a double challenge—to expand both the range and the capacity of needed services.

Communities used different service delivery strategies. One approach was to organize community providers to expand capacity by making effective use of existing resources. AIDS demonstration projects supported this approach in two communities we studied. As another approach applicable where relatively few physicians, hospitals, and other providers have been active in AIDS care, officials advocated mainstreaming or integrating AIDS care into the general health delivery system to expand capacity and meet the growing demand. One state implemented a statewide AIDS referral and follow-up system for this purpose.

Several communities also recognized the need to expand AIDS services to reach minorities and IV drug users. In two communities, local public health clinics, federally supported community health centers, and maternal and child health programs—which already were treating these groups—were used to deliver primary AIDS care.

Chapter 4

Medicaid Is a Leading Payer for AIDS Services

While private health insurance is the principal source of payment for AIDS services, Medicaid is estimated to cover as many as 40 percent of AIDS patients and pay 25 percent of AIDS service bills. Although data were limited, we found that Medicaid is a leading payer for AIDS services in the five communities we reviewed. Increasing AIDS caseloads are expected to increase total Medicaid expenditures for AIDS in those communities and states. As a result, the states will face greater pressures to balance the needs of AIDS patients and other Medicaid recipients, including the elderly, women, and children.

State Medicaid programs are complex systems for AIDS patients to negotiate, as they are for other recipients. Government and health officials in the five communities we reviewed reported problems with eligibility, limited service packages, and low reimbursement rates that in some cases prevented Medicaid programs from serving AIDS patients as effectively as possible. These problems were not unique to AIDS patients, but sometimes were accentuated for them.

Medicaid Is a Leading Public Payer

Medicaid is an important source of payment and the leading public payer for AIDS care in the five communities we reviewed. Available studies indicated that Medicaid paid anywhere from 30 to 50 percent of inpatient AIDS care costs or charges.[1] Although average expenditures per Medicaid-eligible AIDS patient had declined in most communities, total AIDS expenditures in state Medicaid programs were expected to increase with growing caseloads.

No clear trends were apparent in the share of AIDS bills paid by Medicaid relative to private payers, although limited data in the states of Connecticut and Maryland and in the city of Philadelphia suggested that Medicaid's coverage for AIDS hospitalizations may be increasing in those areas. The extent of uncompensated AIDS care was unclear.

Medicaid was the leading single payer for AIDS care in Connecticut, where a survey by the state hospital association found that Medicaid paid 40 percent of AIDS inpatient charges in fiscal year 1986, a figure that increased to 47 percent in 1987, and was projected at 55 percent in

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[1] We found no consistency in the availability or quality of AIDS costs, charges, and financing data among the communities and states. Available information most often came from local studies that were limited to hospital charges or to selected groups of hospitals. There was little information on expenditures for nonhospital outpatient care. Officials were unaware of any documentation or estimates to determine Medicaid's share of AIDS care costs in Louisiana or Pennsylvania.

1988. The same survey showed the private insurance share of such costs as declining from 41 percent in 1986 to 36 percent in 1987.

Medicaid is an important payer for AIDS inpatient care in Philadelphia and Maryland as well. Special studies in Philadelphia found that Medicaid has paid for 40 to 50 percent of AIDS hospitalizations since 1986, and private payers have covered most of the remainder. A state health department study of AIDS hospitalizations in Maryland from 1985 through 1987 found that Medicaid paid 24 to 28 percent of the admissions, Blue Cross paid about 26 percent, commercial insurers paid 20 percent, and at least 14 percent were self-pay or uninsured. According to the study, Medicaid-eligible AIDS patients in Maryland increased from 23 percent of the state's AIDS patients in 1985 to 43 percent in 1987, and could increase to 50 percent in 1988.

In Washington, however, Medicaid's share of AIDS hospitalization charges statewide averaged about 30 percent for the period 1985 through 1987. Commercial insurers and Blue Cross paid for 40 to 50 percent of AIDS hospitalizations, and an independent health maintenance organization paid about 10 percent, suggesting that approximately 10 percent of AIDS patients in Washington may be self-pay or uninsured.[2]

Estimates of Medicaid AIDS Costs and Expenditures Vary

Although some of the states we reviewed had developed estimates of AIDS costs to their Medicaid programs, the estimates varied widely. For example, Connecticut estimated its share of Medicaid expenditures for AIDS (excluding federal matching funds) at $1.4 million in fiscal year 1987, $2.3 million in 1988, and up to $5 million for 1989. Maryland estimated 1988 state expenditures for Medicaid AIDS care in the broad range of $5.6 to $12.8 million, depending on the percent of Medicaid-eligible AIDS patients who used services; and Washington estimated expenditures of $1.7 million in 1988 state funds, of which Seattle-King County accounted for about $681,000.

In Pennsylvania, the Medicaid program spent an estimated $3.3 million in state funds for inpatient, outpatient, and long-term care for 534 AIDS patients during the year ending June 1988. Louisiana estimated its expenditures for AIDS care in Medicaid and the state public hospital system at $1.1 million for the year ending April 1988.

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[2] These data were provided in February 1989 by the Washington State HIV/AIDS Epidemiology Unit in Seattle.

In addition, average expenditures per Medicaid-eligible AIDS patient were widely variable in the communities and states we reviewed, in part due to differences in the study methods that produced the local figures. A preliminary review of 1987 claims by the Connecticut Medicaid program revealed average charges of about $35,500 for adults and $53,600 for pediatric patients with AIDS, with about 80 percent of those charges for inpatient care. In contrast, Maryland reported spending an average $16,000 per Medicaid-eligible AIDS patient per year from 1985 through 1987, and 77 percent of those expenditures were for inpatient care.

Washington reported average annual Medicaid expenditures of $27,000 or less per AIDS patient in 1988. Hospital charges for AIDS patients were declining in Washington because people with AIDS, although living longer, are spending fewer days in the hospital.

Little Known About Other Payers and Uninsured AIDS Patients

Limited information suggested that private health insurance plans covered about 40 to 60 percent of bills for inpatient AIDS care in the five communities we reviewed. Medicare, which covered an estimated 1 to 3 percent of AIDS care costs nationwide, was not a significant payer in any of the communities or states. The numbers of AIDS patients who were uninsured could not be determined exactly, but it appeared that less than 15 percent of the AIDS patients were uninsured.[3]

The Connecticut hospital association survey found that 3 to 15 percent of the state's AIDS patients were uninsured for inpatient care. Studies in Maryland suggested at least 14 percent of AIDS patients may be uninsured. About 40 percent of Louisiana's AIDS patients used the state's public hospital system, but the percent of those patients who were uninsured was unknown. The Washington AIDS epidemiology office estimated that about 10 percent of the state's AIDS patients were uninsured. No estimate of uninsured AIDS patients was available for Pennsylvania.

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[3] An estimated 37 million Americans—15.5 percent of the nation's civilian noninstitutionalized population—have no private insurance or public coverage, such as Medicaid, for medical bills, according to the Department of Health and Human Services, National Medical Expenditures Survey, 1987.

Medicaid Eligibility, Service Coverage, and Reimbursement

Medicaid is a federally aided, state-administered medical assistance program that served about 22 million people in fiscal year 1985. Within broad federal limits, states establish program scope and reimbursement rates, and make payments directly to the providers who render services.

The nature and scope of a state's Medicaid program are contained in a state plan, which, after approval by the Department of Health and Human Services, provides the basis for federal funding. The statutory funding formula provides a higher federal share to states with lower per capita income, and establishes a minimum federal payment of 50 percent and a maximum of about 80 percent.

State Medicaid Programs Cover Eligible AIDS Patients

Medicaid eligibility criteria are among the most complex of all assistance programs. States must provide Medicaid coverage to the categorically needy. These essentially are people who receive cash payments from the Aid to Families With Dependent Children (AFDC) and Supplemental Security Income (SSI) programs.[4] [5]

States also can extend Medicaid coverage to the medically needy, a group that essentially includes people who meet all the nonfinancial criteria for assistance, but whose income and resources are considered insufficient to meet their medical needs. In what is called "spend down," persons or families with incomes above the medically needy income standard can deduct certain expenses to establish eligibility for Medicaid. In 1986, 36 states, including the five we reviewed and the District of Columbia, had medically needy programs.[6] [7]

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[4] SSI, a federally administered income assistance program, was established in 1972 under Title XVI of the Social Security Act. As of September 1988, 4.4 million people received SSI cash benefits; about one-third were eligible by virtue of age (over 65), two-thirds were disabled, and 2 percent qualified due to blindness. Total program expenditures for fiscal year 1988 were over $12 billion.

[5] Fourteen states (including Connecticut) limit Medicaid coverage of SSI recipients by requiring them to meet more restrictive eligibility standards. States choosing this option must allow applicants to deduct medical expenses from income to establish eligibility.

[6] In addition to meeting income limits, Medicaid applicants' assets must be within specified limits. For example, to qualify for Medicaid as an SSI recipient in 1988, an applicant could have a home of any value but could not have liquid assets worth more than $1,900 for an individual and $2,850 for a couple. Under certain circumstances, states can impose more stringent asset limits for SSI beneficiaries. Asset limits for medically needy programs vary by state, but must be (1) at least as liberal as the highest limits allowed for cash assistance recipients in the state and (2) the same for all covered groups.

[7] States also can extend Medicaid coverage to certain groups of institutionalized persons. The five states we reviewed covered these groups.

Most AIDS patients qualify for Medicaid by virtue of their eligibility for the SSI program. As a result of a directive by the Social Security Administration in 1983, people meeting the Centers for Disease Control's AIDS case definition are presumed to be disabled for purposes of SSI eligibility. Individuals with symptomatic HIV infection who do not meet CDC's AIDS definition are not presumptively disabled, but may be judged disabled by the normal SSI review process. A disabled person who meets SSI's income and assets criteria receives SSI cash benefits and, in most states, is automatically eligible for Medicaid as a categorically needy recipient. Women and children with AIDS also may be Medicaid-eligible as AFDC categorically needy recipients. AIDS patients who do not qualify for Medicaid through SSI because their income and assets are too high may meet the criteria for eligibility as medically needy recipients or may spend down to qualify.

Medicaid programs in the five states we reviewed covered categorically and medically needy groups, and all but Louisiana covered persons eligible for SSI or AFDC even if they did not receive such cash benefits. The states did not have data on numbers of people with AIDS who became eligible for Medicaid through these different programs, but studies in two states showed increased total numbers of Medicaid-eligible AIDS patients.

Connecticut's Medicaid management information system began tracking recipients with AIDS in 1987, when AIDS-related diagnostic codes were added to the Medicaid claim form. According to this data system, Connecticut had 67 Medicaid recipients with AIDS in 1987; 184 in 1988 (when there were about 270,000 Connecticut residents in the program); and officials estimated there would be 215 recipients with AIDS in 1989. In addition to these cases meeting CDC's reporting definition, there were nearly three times as many Connecticut Medicaid recipients who had HIV-related illnesses.

Officials in Maryland estimate that 30 to 40 percent of people with AIDS are on Medicaid at some time during their illness, and Medicaid's role may continue to increase. As noted above, the proportion of Maryland AIDS patients who were Medicaid-eligible increased from 23 percent in 1985 to 43 percent in 1987. Medicaid officials also are concerned because more nonresidents are seeking AIDS treatment in Maryland, and many of them may become Medicaid recipients. Early in 1989, almost half of the 1,550 AIDS cases in Maryland's statewide patient registry (which includes all payers) were estimated to be nonresidents.

The Louisiana Medicaid director and administrators at the public Charity Hospital of New Orleans reported that Medicaid's low income eligibility threshold ($374 per month for a single person) excludes many residents, including those with AIDS. Consequently, uninsured AIDS patients who do not qualify for Medicaid depend on the state's public hospital system, which is suffering from funding cutbacks.

In New Orleans, officials reported problems getting people with AIDS qualified for the federal SSI and Social Security Disability Insurance (SSDI) programs, despite their presumed disability status. A volunteer retiree from the local Social Security office helped resolve this problem by working with AIDS patients and Social Security staff to ensure that eligible people received benefits.

Variations in Medicaid Service Coverage Affect AIDS Care

Medicaid regulations mandate that participating states cover certain basic health services for all categorically needy recipients, including inpatient and outpatient hospital services, physician services, skilled nursing facility services, and home health care, which often are needed by people with AIDS. States also can offer specified optional services, including home and community-based services, inpatient psychiatric services, prescribed drugs, dental services, and private-duty nursing.

States may impose limits on mandatory and optional services by restricting the number of inpatient hospital days or physician visits allowed, requiring prior authorization for specified services, or requiring copayments for optional services. States frequently limit inpatient, hospital-based outpatient, and physician services. States also may choose not to cover all services for optional eligibility groups, such as the medically needy and noncash AFDC and SSI recipients.

The range of services covered by Medicaid varied among the five state programs we reviewed, and these variations affected Medicaid-eligible AIDS patients as well as other recipients. For instance, Louisiana limited Medicaid coverage to 10 inpatient days per year and, along with Washington, covered a limited number of physician visits.

AIDS patients have extensive and variable health service needs, which range from acute through chronic care and may involve many different providers. In the communities we reviewed, Medicaid recipients with AIDS were reported to have particular difficulties obtaining nursing home care, hospice care, home health nursing, and case management services. The officials we interviewed perceived many of these difficulties as relating primarily to low Medicaid reimbursement rates, but they said service coverage rules, provider practice patterns, and other factors also played a part. (See ch. 3 for discussions of how Medicaid rules and reimbursement rates reportedly affected availability of certain services.)

States Can Use Medicaid Waivers to Expand AIDS Services

Eligibility and service coverage in state Medicaid programs must be "disease neutral." In other words, Medicaid programs generally cannot deny or reduce services or provide additional services to individuals with a particular disease or condition.[8] In some cases, however, states have the option of providing special service packages for particular groups of recipients under approved Medicaid waivers.

The Congress acted in 1986 to permit state Medicaid programs to develop special service packages for people such as those with AIDS and HIV infection. States may apply to the Health Care Financing Administration (HCFA) for Medicaid home and community-based services waivers (commonly called HCBS or section 2176 waivers) or to provide targeted AIDS case management services.[9] As of June 1989, only seven states and none of those we reviewed had implemented Medicaid HCBS waivers to expand noninstitutional services for people with HIV infection.[10] Only Washington had a case management services waiver targeted to AIDS patients.

The Medicaid HCBS waiver is a potentially valuable tool for serving AIDS patients because it allows a range of health and support services to be provided in homes and community settings instead of in hospitals and nursing homes. An HCBS waiver application, however, must demonstrate

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[8] There are exceptions to this rule; for example, early periodic screening, diagnosis, and treatment services for children under 21 years old only.

[9] The Medicaid HCBS or section 2176 waiver option has been available since 1981, and the Omnibus Budget Reconciliation Act of 1986 permitted section 2176 waivers suitable for people with AIDS and HIV infection. The Consolidated Omnibus Budget Reconciliation Act of 1985 gave states the option of offering case management as a Medicaid benefit for specified populations, and the 1986 budget act identified AIDS and HIV-infected patients as a group that could receive case management services under Medicaid.

[10] New Jersey was the first state to obtain an HCBS waiver for AIDS and HIV-infected patients in March 1987. As of June 1989, other states with approved HCBS waivers for AIDS included California, New Mexico, Ohio, Hawaii, South Carolina, and Missouri; applications for Pennsylvania and Florida were under review by HCFA. Illinois and North Carolina treated AIDS patients under HCBS waivers that were not specific to AIDS.

that the proposed service package will be cost-neutral. States must provide assurances that waiver beneficiaries would otherwise require institutional care under Medicaid and that per capita Medicaid expenditures will not increase as a result of the waiver.

In summer 1988, state health department officials in Connecticut, Pennsylvania, and Louisiana told us that they were developing AIDS HCBS waiver applications. Washington began developing an application in November 1988. In June 1989, none of these applications had been approved, and only Pennsylvania's plan was under active review by HCFA. Separate from its AIDS waiver application, Connecticut amended its Medicaid program to add coverage for personal care (homemaker and companion services), extended private-duty nursing, and adult day care for all Medicaid recipients, including those with AIDS.

During an AIDS needs assessment process in 1987, Maryland considered applying for a Medicaid HCBS waiver but decided against it. Because Maryland's inpatient expenditures for AIDS patients were relatively low (about one-third the level of expenditures in New Jersey), expected savings to be gained from substituting outpatient care for hospital services were thought not to be large enough to support expanded HCBS services. Maryland officials said the decision not to apply for an AIDS HCBS waiver may be reconsidered in light of more recent AIDS hospital cost figures.[11]

Medicaid Reimbursement Usually Does Not Reflect Higher AIDS Care Costs

Regardless of differences in state reimbursement systems, Medicaid programs generally pay less than private insurers for any given health service. Thus, Medicaid recipients may be less attractive to service providers than private-pay patients. This problem may be worse for AIDS patients under Medicaid because they are widely perceived as more costly to care for than other patients. Some health providers, therefore, may be reluctant to treat AIDS patients, especially if they are Medicaid recipients.

In the five communities, providers reported that low Medicaid reimbursement rates made nursing home care, home health nursing, mental health care, and a number of outpatient services less readily available to Medicaid recipients with AIDS than to Medicaid recipients without AIDS or to AIDS patients with private insurance. Providers also reported that

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[11] A 1988 study of Medicaid expenditures for people with AIDS by Maryland's AIDS Administration staff suggested that hospital cost figures used in the 1987 decision were low, both because hospital costs were underestimated and because Medicaid covered only about one-half of hospital charges.

inpatient reimbursement often did not reflect the full costs of treatment for AIDS patients.

With regard to inpatient care, the five state Medicaid programs we reviewed used prospective reimbursement systems.[12] In some of the programs, AIDS patients appeared to be more costly to care for than other patients, even when compared with other patients in the same diagnosis related group (DRG) classification for inpatient care. AIDS is a relatively new disease, and the state Medicaid programs had not established separate DRGs for AIDS patients or adjusted the most frequently used AIDS DRGs to reflect the increased costs of AIDS care that result from longer-than-average inpatient stays, more intensive care days, more nursing time, and infection control procedures. Consequently, Medicaid programs in Connecticut, Pennsylvania, Maryland, and Washington paid hospitals substantially less for AIDS inpatient care than the hospitals charged private payers. Officials in Louisiana were unable to provide data on this matter.

Connecticut Medicaid paid for inpatient care based on an average length of stay for all Medicaid patients of about 6 days. AIDS patients, however, averaged 17 days per admission. Maryland Medicaid covered the statewide average number of inpatient days per stay in each diagnostic group. The average length of stay for all diagnoses was 9.6 days, compared with an average 16.5 days per Medicaid-eligible AIDS admission.

Pennsylvania's Medicaid program reimburses hospitals a predetermined amount per admission based on the patient's primary DRG at admission. State officials reported that AIDS patients are more costly to care for than other patients in the same DRG category, but the Pennsylvania system does not include DRGs specifically for patients with HIV infection.

An analysis of AIDS care charges and reimbursements in the state of Washington, using 1986 data, found that Medicaid reimbursed about 65 percent of combined hospital inpatient, outpatient, and physician charges for treating AIDS patients. Another study of AIDS hospitalizations

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[12] Since Medicare implemented its diagnosis related groups (DRG) prospective payment system in 1983, most state Medicaid programs have replaced retrospective payment based on reasonable costs or charges incurred with prospective payment. The Medicaid reimbursement systems in Pennsylvania and Washington were DRG based; Connecticut and Maryland used all-payer rate-setting methods; and Louisiana reimbursed hospitals on a target rate per case basis. Three of the states—Connecticut, Maryland, and Washington—also applied prospective payment to nursing home care, while Pennsylvania paid on a cost basis and Louisiana set statewide rates by level of care. With the exception of Louisiana Medicaid, which paid prevailing charges, the programs reimbursed physician services according to a fee schedule.

in 1984 and 1985 found that AIDS admissions were substantially more expensive than non-AIDS hospitalizations in the two most frequently used DRGS. AIDS admissions with pneumocystis carinii pneumonia were longer and more expensive than admissions for all other AIDS-related conditions.[13] The study concluded that AIDS-specific DRGS might be necessary to reflect the higher costs of caring for AIDS patients.[14]

Some of the states we reviewed were considering adjusting their Medicaid reimbursement systems to reflect the costs of AIDS care, but by the end of 1988 none had taken action. Washington Medicaid officials said DRGS for AIDS care would be reevaluated in 1989. Connecticut was considering higher reimbursement rates for the three hospitals that were caring for the largest numbers of AIDS patients.

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[13] Pneumocystis carinii pneumonia, caused by a protozoan, is the most common cause of death reported for AIDS patients.

[14] Lafferty, William E., et al., "Hospital Charges for People with AIDS in Washington State: Utilization of a Statewide Hospital Discharge Data Base," American Journal of Public Health, Vol. 78 (Aug. 1988) pp. 949-952.

Conclusions and Implications for Public Health Policy

The broadening geographic, demographic, and cost implications of the HIV epidemic raise concerns across the country about how care will be provided to people with AIDS and HIV infection, as well as how the health care system in general may be affected by growing caseloads. As the epidemic continues, policymaking responsibilities at the federal, state, and local levels are likely to become more pressing. To help ensure prudent decisions, much more information about the epidemic and about problems and successes in providing care for people with the disease will be needed.

National trends in the epidemic compel greater attention to AIDS policy at the federal level. AIDS is no longer confined to major urban areas, and sooner or later most communities will have to deal with providing care for the ill. Prevention and education programs as well as delivery and financing of health services should be tailored to the characteristics of each community's AIDS population—with special concern for the growing numbers of IV drug users, minorities, women, and children at risk.

More effective treatment options are becoming available that, although they cannot cure AIDS, can prevent associated illnesses and prolong survival. As a result, AIDS medical care is evolving from acute, hospital-based care to more chronic, subacute care using drug therapies that can be delivered on an outpatient basis, with community-based nursing care and social support services.

Research Is Necessary on AIDS Service Delivery and Costs

Our review of five communities demonstrates that federal, state, and local policymakers will need better information to make informed decisions as the AIDS epidemic continues. Because AIDS is a new disease, relatively little information is available to guide communities on what services are most useful to AIDS patients, how services should be delivered, what levels of utilization should be expected, and how quality of care should be judged. These questions bear on the resources that will be needed to deliver AIDS services and the costs of care. The federal government supports some research on these subjects at the National Center for Health Services Research and at HCFA.

In addition to funding AIDS health services research, the Public Health Service also could explore how existing public programs could contribute to community responses to AIDS. For example, health programs for low-income and minority populations—such as the community and migrant health centers and maternal and child health programs—currently serve people who may have or be at risk of HIV infection. These programs, therefore, should be prepared to provide primary care and appropriate referral for infected patients in addition to providing education to prevent the spread of AIDS.

Federal Support for AIDS Service Delivery Has Been Limited

The federal government has invested most of its AIDS funding—currently about $1.3 billion per year—in biomedical research, education, and prevention activities. In addition, the federal share of Medicaid expenditures for AIDS patient care in 1989 is expected to reach $490 million. These federal funding commitments can be expected to grow with increasing caseloads.

Federal support to help communities prepare for AIDS service delivery, however, has been limited. About $60 million in federal funds have been allocated through the Health Resources and Services Administration's (HRSA's) adult and pediatric AIDS service demonstrations and related projects to communities in need because of their relatively large AIDS caseloads.

The national response to the Robert Wood Johnson Foundation's (RWJF's) second AIDS grant program in summer 1988 demonstrated that many smaller communities believe they need help to develop better AIDS services. Local officials and providers in Seattle told us that RWJF and HRSA funding helped support development of a continuum of AIDS care services; in New Orleans, the RWJF grant provided the focus for organizing services around the Charity Hospital outpatient AIDS clinic. Officials in Baltimore and New Haven said their inability to obtain special AIDS project funding made organizing a coordinated community response to AIDS more difficult.

We believe providing relatively small demonstration grants now for AIDS service planning and coordination to a larger number of communities, including those with a low incidence of HIV infection or AIDS cases, could have positive effects on innovative AIDS service delivery. This could result in reduced federal and state expenditures for AIDS care if communities can provide services through alternatives to costly hospital care, such as home and community-based services. Both public and private payers, therefore, have a financial stake in ensuring better health delivery systems for people with AIDS at the community level.

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How Five Communities Developed AIDS Services

The general objective of AIDS service systems in each community is to provide appropriate, accessible services tailored to community needs, at a reasonable cost. In New Haven, Philadelphia, Baltimore, New Orleans, and Seattle-King County, variations in key factors of community response led to different types of AIDS service networks. Nonetheless, the communities encountered some similar problems, and some developed innovative approaches to solving them.

We summarize below the unique features of the AIDS populations in the cities we reviewed and describe the timing, important events, and roles of participants who organized AIDS services in the five communities.

IV Drug-Related and Pediatric Cases Increasing in New Haven

The city of New Haven was the smallest of the communities we reviewed, but it had the highest prevalence of reported AIDS cases. As of June 1988, 142 AIDS cases per 100,000 population had been reported in New Haven, and 62 patients were living. This prevalence rate greatly exceeded the average of 28 AIDS cases per 100,000 throughout the United States and 26 cases per 100,000 in Connecticut. AIDS cases are widely distributed throughout Connecticut, with about 20 percent of the state's caseload in New Haven and another 30 percent in Hartford and Bridgeport.

In New Haven, AIDS cases among IV drug users and children are increasing more rapidly than cases among homosexual men. Only 25 percent of New Haven's cases were homosexual and bisexual men, compared with 63 percent of U.S. cases; about 55 percent of the cases were IV drug users, compared with 19 percent nationwide. In addition, 11 percent of New Haven's cases have been transmitted heterosexually, which is almost triple the U.S. rate.

Fourteen percent of New Haven's AIDS caseload was Hispanic—the largest in our review—while 65 percent of the cases were in blacks and 20 percent were in whites. Compared with the nation, New Haven also had a larger proportion of women (27 vs. 9 percent) and children (about 6 vs. 2 percent) with AIDS. The high incidence of women and children with AIDS was directly linked to IV drug use; many of these women and nearly all the children were minorities and poor. Adolescent drug use was seen as a growing problem with serious implications for the spread of HIV in New Haven.

New Haven's Response

The initial impetus for community response in 1983 came from white homosexuals, who were first affected by the new disease. A gay community voluntary organization, AIDS Project New Haven, and the Yale-New Haven Hospital assumed leadership in responding to AIDS and have continued to be major participants. By 1986, however, these two organizations recognized that about 80 percent of New Haven's AIDS cases were minority IV drug users and their sexual partners.

On the basis of these groups' recommendation, the mayor of New Haven convened an AIDS Task Force to function through the New Haven Department of Health and serve as the AIDS coordinating body for the city. To be more responsive to minority community needs, the task force restructured itself to include more minorities and in 1987 helped establish AIDS education and outreach groups for women, Hispanics, and blacks.

In 1983, Connecticut's Department of Health Services hired an AIDS epidemiologist to conduct statewide surveillance; and, in 1985, it was designated lead agency for AIDS by the governor. The governor's Human Services Cabinet identified AIDS as its highest priority and in 1988 issued an inventory of state actions on AIDS and a draft of state AIDS policies. A state agency has taken the lead in developing a successful foster home placement program for HIV-infected children, including those in New Haven.

The lead voluntary organization, AIDS Project New Haven, reorganized in 1987 to increase communication with and participation by minorities and IV drug users. In 1988, about 250 volunteers worked with the project, and a campaign to recruit more minority AIDS service volunteers was planned. The project and New Haven providers collaborated in summer 1988 to apply for Robert Wood Johnson Foundation (RWJF) funding for needed service coordination and case management services, but the proposal was not funded.

A few private health providers and community organizations deliver most of the AIDS health services in New Haven. Yale-New Haven Hospital and one community health center provide a disproportionately large share of inpatient and outpatient medical services. The community health center treats a large number of HIV-infected persons who are IV drug users, low-income, or homeless. General health services for these people are uncoordinated, fragmented, and limited in part by available resources; and increasing AIDS caseloads further strain these public providers.

There is no public hospital in New Haven. The costs associated with caring for persons with AIDS who are on Medicaid or who are uninsured, therefore, are borne by private health providers, such as Yale-New Haven Hospital, St. Raphael's Hospital, community health centers, and home health agencies. None of New Haven's nursing homes admits AIDS patients.

Most Philadelphia AIDS Cases in Homosexuals and Minorities

Philadelphia is the largest community in this review in terms of total population, cumulative reported AIDS cases (938), and people with AIDS alive in June 1988 (over 320). With 57 AIDS cases per 100,000 population, the prevalence of AIDS in Philadelphia was more than double the U.S. rate. Philadelphia's AIDS problem dominated the state because the city had more than one-half of the state's AIDS cases but only 14 percent of its population.

The racial characteristics of Philadelphia's AIDS population differed from those of the U.S. AIDS population. Fifty-three percent of Philadelphia's AIDS cases were black, although blacks make up only 38 percent of the general population. About 70 percent of Philadelphia's AIDS cases among blacks were reported as due to homosexual and bisexual transmission. Among Hispanics, about half of the AIDS cases were due to IV drug use. Of all AIDS cases in Philadelphia, 75 percent resulted from homosexual and bisexual transmission. Whites with AIDS in Philadelphia were almost entirely (90 percent) homosexual or bisexual men.

Nine percent of Philadelphia's AIDS cases were reported among IV drug users, and another 9 percent were reported among homosexuals who also were IV drug users. Thus, the proportion of IV drug-related cases in Philadelphia was less than the U.S. average (26 percent for these two transmission categories combined). Moreover, only 2 percent of Philadelphia's reported cases were transmitted heterosexually, and women and children comprised a smaller share of the AIDS population than was the case nationwide.

Philadelphia's Response

Public and private officials we interviewed agreed that Philadelphia's response to AIDS has been slow. Across all racial and ethnic groups, the Philadelphia AIDS population is 75 percent homosexual, with very little crossover among homosexual groups of different races. Some respondents suggested that Philadelphia's efforts were hampered by the community's attitudes about homosexuality and fear about the spread of AIDS.

Philadelphia was the only major city in the country not to submit an application for Health Resources and Services Administration (HRSA) adult AIDS service demonstration funding in 1987. In addition, the city provided little funding and support for agencies delivering AIDS services until 1987. The state has not taken an active role.

Instead, community-based organizations and individual community leaders have been the impetus behind the development of AIDS services in Philadelphia. From 1982 to 1987, these organizations, together with an informal coalition of doctors, volunteers, and other individuals, provided the only leadership and services available for people with AIDS. The turning point in Philadelphia came in July 1987, when the mayor established an AIDS Activity Coordinating Office in the city health department, based on advice from the AIDS Advocacy Coalition of community organizations. Community leaders voiced support for the director of this new office and believe the city now has emerged as a leading participant in an effort to build a network of AIDS services.

A unique factor in Philadelphia's response to AIDS was the privately funded Philadelphia Commission on AIDS, which operated from September 1987 until October 1988. The commission was created to bring together leaders of the Philadelphia community to oversee a year-long assessment of AIDS, including special studies on financing and attitudes, conferences to educate leaders of different community groups, and preparation of a comprehensive AIDS service needs plan for 1991 by a private consulting firm. The commission recommended nonbinding citywide actions, including reallocation of existing resources to support expansion of services to speed up Philadelphia's slow response to AIDS needs.

The city health department's AIDS office has broad responsibility for coordinating AIDS activities ranging from disease prevention to health and social service delivery. The office supports community-based AIDS organizations with special attention to minority organizations, such as BEBASHI—Blacks Educating Blacks About Sexual Health Issues. The AIDS office plans to spend about 75 percent of its 1989 budget on services contracted to community organizations.

Philadelphia has a wide variety of health resources, with about 40 general hospitals within the city limits, 6 of them medical school teaching hospitals. None of the hospitals took a leadership role in developing comprehensive AIDS service programs. Philadelphia hospitals began to experience a significant decline in profits in 1987, and in an overbedded, highly competitive market, the hospitals may have been concerned about attracting too many Medicaid and uninsured AIDS patients. The city does not have a public hospital.

A few hospitals provide most of the inpatient AIDS care, but patient populations varied considerably among them. Most white homosexuals use the University of Pennsylvania and Graduate hospitals. On the other hand, Temple University Hospital and Giuffre Medical Center serve AIDS patients who are mostly poor and IV drug users. Both of these hospitals are experiencing financial difficulties. Temple University Hospital, which provides a large amount of indigent care, is the only state-affiliated medical school hospital in the city. Temple receives about $2.5 million annually from the state for indigent care; about one-half of its patients are Medicaid beneficiaries.

Inadequate capacity and access barriers, including inability to pay, affect the availability of some types of health services needed by persons with AIDS in Philadelphia. None of the hospitals offers organized, comprehensive inpatient and outpatient AIDS services. General outpatient services in the city's nine public health clinics were limited. One of the centers provides sexually-transmitted disease services for persons with AIDS, and only one of five community health centers (with partial federal funding) for low-income persons had an organized AIDS program. Local officials said home-based hospice services were available for private pay patients only, since Pennsylvania Medicaid does not cover hospice. Low reimbursement also may have contributed to reduced access to mental health and psychiatric services and home health nursing and attendant care, according to officials we interviewed.

Blacks Overrepresented Among Baltimore's AIDS Cases

As of June 1988, of the 535 AIDS cases reported in Baltimore, nearly 200 were living. This represented 70 cases per 100,000 population, a prevalence rate more than twice the U.S. average and Maryland state rates. Baltimore had 18 percent of the state's population and 41 percent of its AIDS cases.

A disproportionate share of Baltimore's AIDS cases is found among blacks. Whites are 44 percent of the population but only 32 percent of the AIDS cases; while blacks, 55 percent of the population, make up 67 percent of the AIDS cases. Nearly all pediatric cases were black.

Although this demographic distribution of AIDS cases is strikingly different from the United States, AIDS transmission patterns in Baltimore were similar to those reported nationwide. Of Baltimore's AIDS cases, 61 percent were transmitted homosexually compared to the U.S. rate of 63 percent; and the proportion of IV drug users with AIDS (23 percent) was also close to the national average of 19 percent. Baltimore had more than the national average of women (13 percent) and children (3 percent) with AIDS, however, and these cases were almost all IV drug-related. Of women with AIDS in Baltimore, 66 percent contracted it through their own IV drug use, compared with 26 percent who were infected by their sexual partners.

Baltimore's Response

The initial response to AIDS in Baltimore came from the white homosexual community, which in 1983 organized the Health Education Resource Organization (HERO), the first community volunteer services agency for AIDS. There was no AIDS voluntary organization in the black community until 1987, when EarthTide was founded. EarthTide is active in developing housing for persons with AIDS.

A gay clinic for treatment of sexually-transmitted diseases established in the late 1970s was involved early in AIDS outpatient services. The two university medical centers in Baltimore—Johns Hopkins Hospital and the University of Maryland—began developing AIDS services in 1984 and 1985. The Baltimore City Health Department began responding to AIDS by initiating surveillance in 1983 and AIDS education and prevention activities in 1985 through contracts with HERO and other community organizations.

Maryland state government focused attention on the problems of AIDS by appointing a governor's AIDS task force in 1985, which reported its recommendations in 1986. The task force continued to function in 1987 and 1988 as the governor's advisory council on AIDS. Reorganization of the state health department in summer 1987 included establishment of an AIDS Administration as lead agency, and state involvement in service development, planning, and problem solving continues to grow.

Health services for AIDS in Baltimore are relatively abundant. There is no public hospital, but so far persons with AIDS have had access to inpatient care regardless of ability to pay. Although almost all Baltimore hospitals have treated persons with AIDS, the two university medical centers provide most of the inpatient care and organized outpatient clinic services.

Both Johns Hopkins Hospital and the University of Maryland sought adult AIDS service demonstration project funding, but were not successful. Officials we interviewed at organizations in Baltimore suggested that the lack of coordination among local service providers may explain the failure to secure RWJF or HRSA adult AIDS service demonstration funds. In fact, some officials identified the lack of a local AIDS services coalition or coordinating body as an important problem in Baltimore's AIDS service system.

These officials also stated that there is no coalition of medical providers. Rather, the two university AIDS care programs tend to go separate ways. There is no comprehensive care system for medical and support services for persons with AIDS. This is frustrating for providers as well as patients.

Representatives of HERO expressed hope that the state AIDS Administration would encourage coalition building to improve service delivery in Baltimore. The state has been active in identifying AIDS service needs and trying to develop responses to them. A state agency manages foster home placement programs for adult and pediatric AIDS patients, for example, and the AIDS Administration is implementing a demonstration Diagnostic Evaluation Unit program designed to develop statewide AIDS referral and care networks supported by case management. The Maryland Medicaid program developed a package of initiatives to help deliver needed services to persons with AIDS, including targeted case management, hospice care, private-duty nursing, and AZT for the uninsured. In addition, Medicaid is implementing a higher reimbursement rate for nursing homes admitting infectious patients, including those with AIDS.

New Orleans AIDS Cases Mostly Among White Homosexual Men

The New Orleans metropolitan area reported 46 AIDS cases per 100,000 population[1] and 602 total cases by June 1988, of which 234 were living. About 65 percent of the metropolitan area's general population was white (in the city of New Orleans only, 43 percent of the general population was white) and whites accounted for about 67 percent of the AIDS cases. Nearly 70 percent of Louisiana's AIDS cases were concentrated in the New Orleans metropolitan area, which had 30 percent of the state's population.

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[1] This prevalence reflects, in part, the inclusion of five parishes surrounding Orleans Parish and the City of New Orleans in the metropolitan area. AIDS surveillance data were not available separately for the city.

Of AIDS patients in New Orleans, 76 percent were homosexual or bisexual men, compared with 63 percent of the U.S. AIDS population. Conversely, CDC data indicated that only 5 percent were infected through IV drug use, compared with 19 percent nationwide. Syringes and needles are not controlled by prescription in Louisiana, and state health officials have speculated that this may reduce the sharing of IV drug equipment, and hence HIV transmission. Consistent with low IV drug-related cases, New Orleans had relatively few women and children with AIDS.

New Orleans' Response

Community response to AIDS in New Orleans began in 1983 with the establishment of a gay volunteer AIDS service organization, the NO/AIDS Task Force. In 1988, that task force and two other organizations—the Associated Catholic Charities' New Orleans AIDS Project and the state health department's Louisiana AIDS Prevention and Surveillance program—are continuing to lead the community response to AIDS.

The Louisiana state and New Orleans city governments have operated under severely constrained budgets in recent years as a result of the loss of oil and gas tax revenues. Since 1985, the state health department's AIDS activities have been entirely supported by federal funds from CDC; only a few staff positions are paid from state funds. The city's health providers have been successful, however, in attracting federal and private funds to support their AIDS programs.

The first special AIDS service project, the New Orleans AIDS Project, was funded late in 1986 by a 4-year RWJF grant. It has provided the core services and a formal coordinating body (the Metropolitan AIDS Advisory Committee, a consortium of service providers) for AIDS services development in the city. Since the RWJF award, New Orleans has received AIDS services support from a number of outside sources.

The New Orleans city health department has not taken an active role in AIDS services development, although it did hire staff in 1988 to conduct minority outreach. Some state health department staff have provided leadership and technical assistance in service development, but the state has been unable to fund AIDS education and service programs.

The state provides a large share of the inpatient care for persons with AIDS through Medicaid and the statewide charity hospital system that is available to anyone who cannot pay. State officials reported that the charity hospital system has suffered from several years of inadequate funding, however, due to the state's fiscal crisis as well as low pay and poor working conditions. Nevertheless, the New Orleans' Charity Hospital has admitted three times more AIDS patients than any other hospital in the city. Private pay and some Medicaid patients use four other private hospitals, and the Veterans Administration medical center also has an AIDS program.

The RWJF-funded New Orleans AIDS Project provides most of the outpatient care and case management services, and it subcontracts for home health and home-based hospice care. Home care services subsidized by RWJF grant funds, however, could terminate in 1991. The only source of housing assistance for persons with AIDS in New Orleans is one group home run by Associated Catholic Charities, and no nursing homes accept AIDS patients.

A patient's insurance status affects where that person will go for health care in New Orleans. Charity Hospital cares for people with AIDS who lack health insurance; but such services as mental health, psychiatric care, and dental care are less available to persons who cannot pay or who are covered by Louisiana Medicaid. Privately insured patients tend to use private physicians and hospitals, but when they lose private sources of payment, they may transfer to Charity Hospital.

Seattle AIDS Cases Are Most Uniformly White and Least Uniformly IV Drug-Related

As of June 1988, Seattle-King County had reported 710 AIDS cases, and of these 276 were living. The prevalence of AIDS in the county was 54 cases per 100,000 population. With 30 percent of the state's population, Seattle-King County had 74 percent of the state's AIDS cases.

Homosexual transmission accounted for a larger share of AIDS cases in Seattle than in any of the other communities we reviewed or the United States in general. In Seattle, 84 percent of the cases were transmitted through homosexual or bisexual contact, compared with 63 percent nationwide. Another 10 percent of Seattle's cases were among homosexual or bisexual IV drug users, and only 2 percent resulted from IV drug use alone.

Whites in Seattle made up a larger share of the AIDS caseload (92 percent) than of the general population (88 percent). Asians, who form a relatively large minority population in Seattle, were less affected by AIDS than the black and Hispanic communities.

Males comprised 98 percent of Seattle-King County's AIDS cases, and there were only three pediatric cases reported as of June 1988.

Although surveillance data do not show significant changes in AIDS cases by transmission in Seattle-King County to date, the proportion of IV drug-related cases is expected to increase somewhat. The Department of Public Health and local AIDS organizations are focusing on preventing IV drug-related AIDS transmission.

Seattle-King County's Response

Among our study communities, Seattle-King County most resembles San Francisco in its response to AIDS. The extremely homogeneous AIDS population, along with a history of cooperation between the gay community and city government, may have contributed to Seattle's early and successful response to AIDS.

Seattle has an unusual configuration of AIDS health resources—an active city-county public health department, a county public hospital, and a major health maintenance organization with its own hospital, in addition to private hospitals. When the first AIDS case was reported in 1982, a network of alliances and a history of working together already existed among the gay community, the University of Washington, the city-county public health department, other local government agencies and organizations, and community physicians.

Inpatient care for persons with AIDS is provided at one of three "centers of excellence"—the public Harborview Medical Center, Swedish Hospital, and Group Health Cooperative of Puget Sound Hospital. Outpatient care is provided primarily by Harborview and Swedish hospitals, along with private physicians and community clinics.

Community-based volunteer service organizations are a key component of the Seattle-King County health care and social service delivery system for people with AIDS. The Northwest AIDS Foundation, established in 1983 by the gay community and health care providers, continues to be the focus for coordinating volunteer services and for filling AIDS service needs as they are identified. Officials estimated that volunteers donated 70,000 hours for providing AIDS services in 1987.

The Seattle-King County public health department in 1983 was among the first local government agencies to allocate funding for AIDS surveillance, risk reduction, education, and clinical assessment of persons at risk. An AIDS task force established by the mayor in 1985 completed a local needs assessment, recommended actions, and provided the framework for long-range planning.

Seattle-King County received an RWJF AIDS service demonstration grant in 1986 that helped coordinate AIDS service development and delivery. The city-county health department, which is grantee for the RWJF and the subsequent HRSA AIDS service demonstration grants, is the designated public lead agency for overall coordination. In addition to its planning and coordination roles, it also provides case management and housing assistance.

The governor of Washington established a state AIDS task force in 1987, which produced a report with policy recommendations that contributed directly to passage of the state's omnibus AIDS bill in March 1988. Organizations and individuals we interviewed in Seattle felt that overall, the health providers, community service organizations, and public health department have succeeded in meeting many service needs of people with AIDS.

Appendix II

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Related GAO Products

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

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