

# New Jersey's Medicaid waiver for acquired immunodeficiency syndrome

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*This article contains data from a study of New Jersey's home and community-based Medicaid waiver program for persons with symptomatic human immunodeficiency virus illness. Major findings include lower hospital costs and utilization for waiver participants compared with general Medicaid acquired immunodeficiency syndrome admissions in New Jersey.*

*Average program expenditures were \$2,400 per person per month. Based on study findings, it is evident that the waiver program is an important means of providing financial benefits and access to services and that comprehensive case management is a critical factor in assuring program quality.*

## Introduction

The human immunodeficiency virus (HIV) epidemic will present major challenges to the U.S. health care system in the coming decade. By the end of 1990, more than 160,000 people in the United States were reported to have acquired immunodeficiency syndrome (AIDS) (Centers for Disease Control, 1991). An estimated \$50 billion will be spent in the 1990s for HIV health care (Pascal et al., 1989). Recent developments in the epidemiology and treatment of persons infected with HIV also bear important consequences for the health care financing and delivery system. Survival time has increased since the early years of the epidemic (Harris, 1990; Lemp et al., 1990; Seage et al., 1990). Improved therapeutics offer the promise of delaying the onset of debilitating symptoms and of longer survival (Hellinger, 1988; Pascal, 1987). Treatment of persons with HIV disease is shifting from the acute care inpatient hospital setting to outpatient and community-based modalities (Arno and Shenson, 1990; Hellinger, 1988). AIDS is now considered to be part of a spectrum of HIV disease and, accordingly, HIV health care models must also incorporate a range of settings for the delivery of services.

In this context, long-term care for persons with AIDS (PWAs)<sup>1</sup> is an important policy issue. As the nature of the disease shifts from the acute to the chronic, interest has arisen in the provision of home health care as a more humane and less costly alternative to long-term institutionalization. There is increasing recognition that HIV health services should be organized along a continuum incorporating both the acute care and the chronic illness management needs of persons with HIV (Benjamin, 1988). As prevalence and survival continue to rise, the direct and indirect costs of HIV will also increase. Home and community-based long-term care

is therefore looked to for potentially providing both the cost effectiveness and the continuity of care required. Little is known, however, about the cost, delivery, and quality of home and community-based services for persons with HIV. In order to make informed policy decisions, there is a need for more analysis of the issues involved and of actual experience to date in providing long-term HIV care.

This article discusses the policy context of long-term HIV services and reports on an empirical study of the Nation's first Medicaid waiver home care program for persons with HIV—the New Jersey AIDS Community Care Alternatives Program. The study is an examination of the populations served by the program, types of services utilized, program costs, service delivery problems, and unmet needs of program participants. Implications of the above for developing models of care that address the multiple needs of persons with HIV are also discussed.

## Policy issues

The experience with HIV highlights gaps in the U.S. health care system, particularly in reference to the organization, delivery, and financing of long-term care services (Benjamin, 1988; Rogers, 1989). In addition, HIV presents special problems related to the nature of the populations affected and the stigma associated with AIDS. The shifting epidemiology of HIV from homosexual males (the majority of whom are white) to intravenous drug users (IVDUs) and their sexual partners is resulting in increased prevalence among the poor and minorities, including women and children. Thus, the second and third waves of the epidemic are occurring primarily among populations with limited access to health care and that rely on Medicaid and other government-financed programs (Pascal, 1987; Scitovsky, 1988).

Existing problems with the organization, availability, and financing of long-term care resources for the elderly limit the ability to provide institutional and home health services to new populations such as PWAs (Crystal, 1989a). In addition, the long-term care delivery system, which is structured around the elderly, is ill-prepared to meet the needs of the younger PWA

<sup>1</sup>Throughout this article, the term "PWA" (person with AIDS) is used when referring to those with symptomatic HIV disease.

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population (Crystal, 1989b). PWAs often require child care, treatment for illicit drug dependence, or other support services oriented toward a non-elderly population. Compared with elderly patients, PWAs frequently present greater medical complexity and have more intensive home health services needs, such as increased nursing care, physician support, personal care, and patient and caregiver education (Preston, Andrews, and Howell, 1989). The system's focus on long-term institutionalization and stable home care service needs is not readily adaptable to the episodic nature of functional disability among PWAs, which calls for more intermittent care (Crystal, Merzel, and Kurland, 1990). In addition, many nursing homes and home care agencies are reluctant to serve PWAs as a result of both the stigma associated with AIDS and low Medicaid payment, despite the higher level of care required by PWAs (Andrews, Welch, and Howell, 1989; U.S. General Accounting Office, 1989). The problem is exacerbated by the general shortage of nursing home beds even for the elderly (Benjamin, 1988; Crystal, 1989a). The lack of long-term care options for HIV results in excessive reliance on the acute care hospital sector to provide such care (Benjamin, 1988; Mechanic and Aiken, 1989) and is a contributing factor in increased length of hospital stays and the strained capacity of inpatient HIV services in a number of cities (U.S. General Accounting Office, 1989; Howell et al., 1989; Kotelchuck, 1989; Marder and Linsk, 1990; Preston, Andrews, and Howell, 1989; Widman, Light, and Platt, 1990).

The financing of HIV care is rapidly shifting from private to public sources, signifying the "Medicaidization" of AIDS (Green and Arno, 1990). Public financing is increasingly important because of the impoverishment of many persons with HIV, as a result of either loss of employment and high medical bills or initial low-income status (Pascal et al., 1989; Vladeck, 1989). In addition, many private insurers restrict their coverage of individuals considered at high risk for HIV (Iglehart, 1987). Increasing survival time will result in more PWAs exhausting or losing their private health insurance and savings, thereby becoming eligible for Medicaid (U.S. General Accounting Office, 1989). These factors, combined with increasing prevalence, indicate that future Medicaid costs for HIV will continue to rise.

Medicaid is estimated to cover about 25 percent of the total national costs of AIDS-related health services (Scitovsky, 1990; Winkenwerder, Kessler, and Stoler, 1989). Approximately 40 to 60 percent of all PWAs eventually come to rely on Medicaid (Pascal et al., 1989; Scitovsky, 1990). The Health Care Financing Administration (HCFA) has predicted that Medicaid expenditures for AIDS will reach \$2.4 billion by 1992, excluding costs for zidovudine (formerly azidothymidine) treatment (Roper and Winkenwerder, 1988). It is estimated that during the 1990s, HIV care will account for 5 percent of national Medicaid expenditures; and in high-prevalence States, 10 to 15 percent of Medicaid expenditures may be spent on HIV services (Pascal et al., 1989). Medicare covers only

about 1 percent of PWAs because of the 2-year waiting period for disabled persons under 65 years of age to qualify for benefits (Winkenwerder, Kessler, and Stoler, 1989). Thus, the burden of financing HIV services is a major issue confronting State governments.

This burden is compounded by the reliance on inpatient hospital services for the provision of much of the care to PWAs. Although use of inpatient care has declined since the early years of the epidemic (U.S. General Accounting Office, 1989; Hellinger, 1988), HIV-related hospital utilization and costs are still relatively high. It has been estimated that hospital inpatient costs account for more than 80 percent of the total medical care costs for AIDS (McCormick, 1990; Scitovsky et al., 1989). Public funding, which covered 25 percent of hospital days for PWAs nationwide in 1984-85, increased to 40 percent by 1986-87 (Moien and Kozak, 1989). In a national survey of 623 public and private acute care teaching hospitals, Andrulis and colleagues found that in 1987, 44 percent of AIDS inpatient admissions were paid by Medicaid compared with 29 percent by private insurance, 2 percent by Medicare, 23 percent self-pay, and 2 percent by prisons (Andrulis, Weslowski, and Gage, 1989). Furthermore, treatment of HIV patients is clustered among a limited number of hospitals. Public hospitals, which have large proportions of self-pay and Medicaid patients, tend to carry disproportionately high caseloads (Andrulis, Weslowski, and Gage, 1989; Scitovsky, 1988).

Despite the heavy dependence on Medicaid, State variations in eligibility and extent of service coverage mean that many PWAs are either uncovered or undercovered by Medicaid (Pascal et al., 1989). The Andrulis survey found that almost one out of every four AIDS hospital admissions nationwide was self-pay. In the South, the self-pay rate was 48 percent, and only 18 percent of AIDS admissions were paid for by Medicaid. Nationwide, the burden of paying for hospital outpatient care falls most heavily on individuals. Fully one-half of all visits were self-pay compared with 31 percent paid for by Medicaid and 15 percent paid for by private insurance (Andrulis, Weslowski, and Gage, 1989). As inpatient use declines, there has been an increase in utilization of outpatient services (Weslowski et al., 1990). Given the low-income status of many PWAs, these figures suggest that there are substantial uncompensated care costs for inpatient and outpatient HIV services provided by hospitals.

The extent of financial strain for patients and facilities as a result of inadequate long-term care financing is unknown because of the limited research in this area. Most studies of the costs and utilization of HIV services focus on analysis of institutional acute care costs, facilitated by the accessibility of hospital billing records. The few studies to date suggest that Medicaid coverage of and payment for institutional and home-based long-term care is insufficient (Andrews, Welch, and Howell, 1989; U.S. General Accounting Office, 1989; Health Systems Agency of New York City, 1989; Keyes, Andrews, and Howell, 1989; Pascal et al., 1989). Medicaid and most private insurance

mechanisms are geared toward payment of acute care, which is more expensive and at times inappropriate. In part because of medically unnecessary reliance on inpatient care when subacute care is unavailable, there are differences in hospital admissions and lengths of stay across communities, accounting for some of the variation in the cost of treating HIV (Scitovsky, Cline, and Lee, 1986). Although community-based services are best viewed as a complement rather than a complete substitute for inpatient care (Benjamin, 1990), community-care initiatives that can reduce hospital length of stay may have an immediate impact on the cost of HIV care, as inpatient care is by far the largest component of HIV medical care costs (McCormick, 1990). There is evidence that although the declining length of hospital stays by PWAs has resulted in a reduction in the annual costs per patient, there has been an increase in the lifetime costs because of longer survival combined with a relatively constant number of annual hospitalizations per person (Seage et al., 1990). Although it appears that medical care expenditures for HIV will continue to rise, the rate of increase may be moderated by mechanisms that can shorten the duration of hospitalization.

The trend of declining inpatient utilization also suggests that the need for community-based health services, including home care, will increase in the coming decade. The lack of both institutional and community-based long-term care services will result in discharges from acute care facilities to the community where needed services are not available or affordable to PWAs. Such services as skilled nursing care are typically unobtainable (U.S. General Accounting Office, 1989; Preston, Andrews, and Howell, 1989). According to some estimates, 10 to 25 percent of PWAs need skilled nursing care (Benjamin, 1988; Rango et al., 1989); surveys conducted in New York City and San Francisco suggest that 12 to 14 percent of PWAs are living at home without needed subacute services (Green, 1990). In New York City, as many as 1,000 PWAs may lack needed home care services (Health Systems Agency of New York City, 1989). Service shortages are particularly severe in suburban and rural communities, where many PWAs return to be cared for by their families (Droste, 1987).

The development of adequate and appropriate long-term care resources for HIV has emerged as a major policy issue. As discussed earlier, the deficiency of resources is related to a variety of factors. Services are unavailable because of inadequate supply, payment disincentives, and the absence of public and private insurance mechanisms to adequately cover required services and all those in need. In addition, there are access problems particular to PWAs that stem from the unavailability of services tailored to their special needs and from provider unwillingness to serve HIV patients. As prevalence of the disease continues to rise, home and community-based alternatives increasingly are looked on as a means of providing needed services and controlling growing Federal, State, and local expenditures for HIV (U.S. General Accounting Office, 1989).

## Home and community-based Medicaid waivers

A major policy initiative designed to create an alternative to costly long-term institutionalization is the Medicaid home and community-based waiver program. Under section 2176 of the 1981 Omnibus Budget Reconciliation Act, HCFA was given the authority to waive certain Federal Medicaid regulations in order to enable States to include in their Medicaid programs home and community-based services targeted to specific populations such as the elderly, disabled, developmentally disabled, and mentally ill. The regulations permit expansion of the eligible population to include persons who otherwise would become financially eligible for Medicaid benefits only upon institutionalization. Regulations stipulate that the cost of Medicaid services provided under the waiver must not exceed the cost of institutional care (Jacobson, Lindsey, and Pascal, 1989). By July 1990, 10 States had developed AIDS-specific waiver programs—California, Florida, Hawaii, Missouri, New Jersey, New Mexico, Ohio, Pennsylvania, South Carolina, and Washington (National Governors' Association, 1990). Several States provided coverage to PWAs under other Federal waiver authority or through expansion of optional services under Medicaid (Jacobson, Lindsey, and Pascal 1989; Lindsey, Jacobson, and Pascal, 1990).

The Federal waiver regulations allow Medicaid coverage of a number of basic categories of service: case management, homemaker, home health aide, personal care, adult day care, habilitation, day treatment, and other partial hospitalization services; respite care, psychosocial rehabilitation, and other services that can include a wide array of such services as private duty nursing, medical supplies and adaptive equipment, transportation, and home-delivered meals. States with AIDS-specific waiver programs vary in the scope of waiver services covered. Among the most frequently covered services are case management, personal care, and adult day care (Jacobson, Lindsey, and Pascal, 1989; Lindsey, Jacobson, and Pascal, 1990).

As of early 1991, there was only one systematic analysis of AIDS-specific waiver programs nationwide. Conducted by RAND, the study focused on experiences in administering the waiver programs. The major advantages to the programs appeared to be the ability to target benefits to the AIDS population, flexibility in service design and delivery, establishing a uniform system of services, and increasing PWAs' access to a comprehensive package of services. Although the AIDS-specific waiver States varied in the size and composition of their AIDS populations, each was motivated to apply for the waiver out of concern for the ability to meet future needs for HIV care and by the incentive of increased Federal matching dollars. A number of other States were deterred from applying because of the difficulty in demonstrating program cost-effectiveness as required in the application process and other cumbersome administrative and reporting requirements. Other States, with both high and low AIDS prevalence, did not apply because they provided

similar services under State plan Medicaid (Jacobson, Lindsey, and Pascal, 1989; Lindsey, Jacobson, and Pascal, 1990).

Because of the recency of these programs, there is limited evidence available for evaluating their performance in improving the availability of home and community-based long-term care options to persons with HIV and in reducing HIV-related Medicaid expenditures. Evidence from evaluations of waiver programs for the elderly and disabled suggests that such programs expand access to services but may not reduce overall expenditures (Capitman, 1986; Kemper, Applebaum, and Harrigan, 1987). The widespread pattern of full occupancy in nursing homes and resulting waiting lists limits the potential to save costs for the impaired elderly through reduction in utilization of institutional services; according to some studies, total costs may be increased because of the additional coverage under the waiver of community-based services for individuals who would not have obtained nursing home placement (Laudicina and Burwell, 1988).

There is some recognition, however, that the experience of waivers with the elderly may not be entirely applicable to the HIV situation. Programs serving the elderly have focused on attempting to avoid or delay nursing home placement. The key issue for HIV is the reduction of inpatient acute care utilization through the provision of home and community-based services (Jacobson, Lindsey, and Pascal, 1989; Mechanic and Aiken, 1989). Because nursing home placement is rarely available to PWAs and the probability of hospitalization in acute care facilities with high per diem costs is greater for people with HIV than is the risk of nursing home utilization by the elderly, there may be greater potential for cost effectiveness in providing home care to PWAs (Benjamin, 1988).

The feasibility of providing home-based care is related not only to issues of payment and health care delivery resources, but also to the social circumstances of patients and their communities. Mobilization of family support and other informal care is a critical element. Informal caregiving by family and friends is the predominant source of care for the impaired elderly while formal services provide less than 15 percent of all care provided to the disabled elderly residing in the community (Doty, Liu, and Wiener, 1985). The frequently noted "San Francisco model" of HIV service delivery is based on a well-developed network of community-based volunteers to provide services in the home (Arno, 1986).

Given the spread of the HIV epidemic into drug-using and low-income populations, questions have arisen concerning the ability to provide home care to persons presumed to lack stable lifestyles and social support networks capable of caregiving. The experience with the New Jersey AIDS-specific waiver is particularly relevant because of the large proportions of minorities and persons with a history of intravenous drug use in New Jersey's HIV population. In addition, reflecting the national picture, the geographic distribution of

cases statewide includes high-prevalence urban communities and suburban and rural areas with fewer cases and less developed service networks.

The following discussion is a report on the New Jersey AIDS Community Care Alternatives Program (ACCAP). Established in 1987, it is the Nation's first AIDS-specific home and community-based care waiver program. The study is based on an evaluation and subsequent analyses of the program's first 2 years of operation. The evaluation was an independent assessment conducted by the AIDS Research Group of the Institute for Health, Health Care Policy, and Aging Research, Rutgers University, on behalf of the New Jersey Medicaid program. The assessment was based on a process evaluation of the program and focused on the implementation of program procedures, quality of services, access to the program and its services, and program expenditures.

## Methods

Analyses were based on comprehensive review of case records, examination of Medicaid claims data, client background information collected on enrollment, and structured interviews with program case managers and a sample of clients.

The New Jersey Medicaid office provided a computer file of demographic and program-related information collected on enrollment for all clients. Client characteristics presented in this article are based on the 675 clients who were enrolled in the program during its first 2 years, March 1, 1987, through February 28, 1989.

Structured interviews were conducted in person with 46 case managers at 26 of the program's 28 case-management agencies. At the time of interview field work, there were approximately 64 active ACCAP case managers. Seven were excluded from interview because they had been employed as ACCAP case managers for less than 3 months. Three served only as backup case managers, and the remaining eight who were not interviewed were unavailable at the time of the site visit. The interview focused on case managers' assessments of service delivery problems and quality of services as well as their performance of case-management activities.

Participant satisfaction and program quality ratings were derived from interviews conducted with a cross-sectional sample of 33 clients. Consent for interview was obtained through the case managers in order to maintain confidentiality and to help improve response rates. A total of 188 names were randomly selected in five stages from a list of cases that were active as of March 15, 1989. Of the 188, 27 percent were ineligible for interview because of death or termination from the program subsequent to sampling. An additional 14 percent were children and were excluded from interview because of their age. Among the remaining 110 cases eligible for interview, 14 refused, 18 were too sick at the time to be interviewed, 19 were not located or were unavailable at the time, 20 were not contacted by the case manager before the conclusion of the field

period, and 6 were not interviewed for other reasons. The final response rate was 30 percent of those eligible for interview.

Comparison of the 33 interviewed cases with all active adults enrolled as of February 28, 1989 ( $n = 310$ ) indicated that the interviewed sample was demographically representative of the active adult caseload. The proportions of males and females, black persons, and HIV risk group categories were almost identical in both groups. Based on other characteristics at enrollment and the nature of sample attrition, interview sample selection was biased toward those in better health.

An extract of the Medicaid claims files provided by the New Jersey Department of Human Services, which contained paid claims for the entire ACCAP population, was also utilized. The computer file included a wide variety of data about the claims, such as the category of service, the dates of service, and the amount paid by Medicaid for the claim. In order to maintain confidentiality, no client names were included in the file. Data presented here are based on actual payments rather than on charges. The computer tape contained claims information from the start of the program in March 1987 until January 31, 1989, for persons enrolled through November 30, 1988. The utilization and cost analyses discussed later pertain to the 538 clients included in the tape who were enrolled during this time period and who had at least one claim by January 31, 1989.<sup>2</sup>

## Program characteristics

ACCAP is available to both persons with AIDS or AIDS-related complex (ARC) and to HIV-positive children up to 5 years of age. The program was implemented in March 1987. As of April 1992, a total of 2,575 persons had been served by the program.

ACCAP provides regular Medicaid State plan coverage, encompassing 27 service categories, in addition to waiver services that are not otherwise payable under Medicaid. The waiver also raises the Medicaid financial eligibility limit from the categorical eligibility level to include persons who would become financially eligible if institutionalized. The income limit as of January 1, 1990, in New Jersey for these institutionally eligible individuals was \$1,158 per month. In addition, eligibility criteria specify that program participants must be functionally impaired with medical and social needs that require care in a long-term care facility. The waiver program allows individuals to choose having their needs met at home instead of in an institution.

The costs of all waiver and other Medicaid services, excluding hospital inpatient care, cannot exceed a cap

<sup>2</sup>The claims file represents the entire utilization experience as of January 31, 1989, for all clients enrolled from March 1, 1987, to November 30, 1988. As a result of the enrollment date criterion, there were 137 clients entering the program between December 1, 1988, and February 28, 1989, who were not included in the claims file. There were no significant differences (chi-squared test,  $p = .05$ ) in background characteristics between the 137 cases and the 538 represented in the file.

that is set at a rate equivalent to the average cost of inpatient acute HIV care in New Jersey. In 1990, the New Jersey cap was \$12,960 per client per month. Nursing home rates were not used for establishing the ACCAP cost cap because of the unavailability of this service for PWAs in New Jersey at the time the program was approved.

In addition to Medicaid State plan services, the New Jersey program provides coverage for the following waiver home care services:

- Case management, which is received by all enrollees.
- Private duty nursing.
- Unlimited hours for personal care assistants in contrast to the 25-hour per week limit under State plan Medicaid.
- Specialized medical day care for persons with HIV.
- Home-based narcotic and drug abuse treatment.
- Intensive individual foster care for children that is paid at a rate higher than usual.
- Specialized group foster care homes for children with HIV.
- Hospice, which was added as a new service in 1990.

A major component of ACCAP is comprehensive case management. Case managers are responsible for planning, coordinating, monitoring, and securing the services needed to maintain the client in the home (Crystal, Merzel, and Kurland, 1990). There are case-management sites for each of the State's 21 counties. Case management for adults is provided by certified home health agencies. Services for children are located primarily at county-based child health agencies; several sites for children are operated by hospital-based programs participating in the State pediatric AIDS network.

Data are unavailable concerning the number of PWAs in New Jersey who are not eligible for the program or who are eligible but not served. There are well-developed referral networks with county Medicaid offices, regional Social Security Administration offices, and local hospitals to ensure that those eligible for the program are enrolled. Program administrators have found that constant outreach to AIDS outpatient clinics is necessary because of high turnover of hospital staff. As a result of these outreach efforts, utilization of the program has increased since the first year. By mid-1991, 85 percent of the 800 program slots were filled, compared with 54 percent of the original 350 slots at the end of the program's first year.

## Population characteristics

As of February 1990, a total of 8,331 cases of full-blown AIDS had been reported to the New Jersey State Health Department's AIDS Registry. This represented 7 percent of all cases reported nationwide (New Jersey State Department of Health, 1990). The demographic and risk group characteristics of the AIDS population in New Jersey are quite different from those of the United States as a whole but reflect the subgroups of PWAs that are increasing most rapidly in the Nation (Table 1). New Jersey has much higher proportions of

persons with AIDS who are female, African-American, IVDU-related cases, or children. Twenty-one percent of all cases reported statewide were female compared with 10 percent of cases reported nationwide. Fifty-nine percent of New Jersey's AIDS cases were IVDU-related (heterosexual and homosexual or bisexual IVDU), and only 28 percent of cases nationwide had a history of IVDU. Twenty-seven percent of AIDS cases in New Jersey were non-IVDU homosexual males, compared with 60 percent of the cases in the United States. Fifty-four percent of PWAs in New Jersey were African-American compared with 27 percent of cases nationwide. Eleven percent of all U.S. pediatric AIDS cases were in New Jersey.

The background characteristics of ACCAP clients who had enrolled by the end of February 1990 and who had received a diagnosis of AIDS at the time of enrollment (that is, excluding a diagnosis of ARC and children who were HIV-positive only) were generally very similar to those of cases reported by the New Jersey State AIDS Registry (Table 1). There were few differences by HIV transmission category and sex. However, the proportion of ACCAP clients with AIDS who were under 13 years of age was higher than the proportion of children in the State AIDS Registry

(7 percent versus 3 percent). Black persons were slightly under-represented in the program compared with the percent of black PWAs statewide (46 percent versus 54 percent).

Eighty-one percent of all clients ever enrolled in the program through February 28, 1989, were diagnosed as having AIDS at the time of enrollment; 16 percent had ARC; 2 percent were HIV-positive children (Table 2). Three-quarters of all program enrollees were male. Racial and ethnic minorities comprised over one-half of all ACCAP participants (46 percent were African-American and 13 percent were Hispanic). Forty percent of all ACCAP participants were white. Children in the program were more likely to be African-American (67 percent) than were adults (44 percent). The median age at enrollment was 35 years for adults and 1 year for children. Fifty-one percent of all clients were categorically eligible for Medicaid upon enrollment.

The predominant mode of HIV transmission among ACCAP clients was intravenous drug use. Intravenous drug use was a means of infection for 61 percent of adult enrollees (Table 2). Twenty-six percent of adults were non-IVDU homosexual males. Eight percent of adults were infected by heterosexual transmission and 3 percent were categorized as hemophiliac or infected

**Table 1**  
**Number and percent distribution of acquired immunodeficiency syndrome cases, by selected characteristics: United States, New Jersey, and the New Jersey AIDS-specific Medicaid waiver program<sup>1</sup>**

Characteristics	United States			New Jersey			New Jersey waiver program		
	Total	Adult or adolescent	Children <sup>2</sup>	Total	Adult or adolescent	Children <sup>2</sup>	Total	Adult or adolescent	Children <sup>2</sup>
Number of cases reported	121,645	119,590	2,055	8,331	8,110	221	889	826	63
<b>Sex</b>	Percent distribution								
Male	90	91	54	79	79	54	76	79	43
Female	10	9	46	21	21	46	24	21	57
<b>HIV transmission group</b>									
Intravenous drug user:									
Heterosexual	21	21	NA	53	55	NA	49	53	NA
Homosexual or bisexual male	7	7	NA	4	4	NA	3	3	NA
Non-intravenous drug user:									
Homosexual or bisexual male	60	60	NA	27	27	NA	23	24	NA
Hemophilia or blood transfusion	4	3	10	3	3	8	2	2	5
Heterosexual	5	5	NA	9	9	NA	10	11	NA
Parent at risk	1	NA	82	2	NA	92	6	NA	89
Other and unknown	3	3	8	2	2	—	7	7	6
<b>Race</b>									
White, non-Hispanic	56	57	22	33	34	20	36	38	11
Black, non-Hispanic	27	27	52	54	53	59	46	46	71
Hispanic	18	15	25	13	12	20	16	16	11
Other and unknown	1	1	—	—	—	—	2	1	6

<sup>1</sup>U.S. and statewide figures are those reported as of January 31, 1990, and February 28, 1990, respectively. Waiver data are for clients enrolled in the AIDS Community Care Alternatives Program by February 28, 1990, with a diagnosis of AIDS at enrollment.

<sup>2</sup>Age 12 and under.

NOTES: NA is not applicable. AIDS is acquired immunodeficiency syndrome. HIV is human immunodeficiency virus. Percents may not total 100 because of rounding.

SOURCES: New Jersey Department of Health: AIDS Cases, State of New Jersey as of February 28, 1990; New Jersey Department of Human Services: Office of Home Care Programs, Client File.

by blood transfusion. Maternal infection was the means of transmission for 87 percent of children enrolled in the program. Among adult females, two-thirds were considered to be infected through IVDU and 19 percent by heterosexual transmission. Fifty-four percent of adult males were categorized as heterosexual IVDU, 5 percent as homosexual IVDU, and 32 percent as non-IVDU homosexual.

Almost three-quarters of all clients ever enrolled in the program were living in the community at the time of enrollment, and 23 percent were admitted from an acute care hospital (Table 2). Less than 1 percent were admitted from a nursing home (as of 1990, there was only one nursing home in the State that had beds available for patients with HIV). Eighty-three percent

of clients were living with someone at enrollment. Thirteen percent of all clients did not have a main caregiver. Primary caregivers were most frequently the parent(s) of the client (42 percent of all enrollees); spouses were the caregivers for 12 percent of clients; 16 percent were cared for by another relative; and 15 percent were cared for by a "friend," probably most frequently referring to lovers.

Forty-one percent of adult ACCAP participants were rated at the time of program intake as requiring some assistance with activities of daily living (ADL) (Table 2). One-third of adults were rated as needing substantial assistance with ADL. Twenty-six percent of adults required complete help with ADL at the time of enrollment, equivalent to skilled nursing facility care.

**Table 2**  
**Number and percent distribution of New Jersey AIDS-specific Medicaid waiver program enrollees, by background characteristics<sup>1</sup>**

Characteristic	All enrollees	Adults <sup>2</sup>	Children <sup>3</sup>	Characteristic	All enrollees	Adults <sup>2</sup>	Children <sup>3</sup>
Total number of enrollees	675	599	76				
	Percent distribution				Percent distribution		
<b>Sex</b>				<b>Living arrangement at home</b>			
Male	75	78	47	With parent or adult child	40	40	44
Female	25	22	53	With spouse	11	12	—
				With other relative	13	14	6
<b>Race</b>				With non-relative	17	15	30
Black, non-Hispanic	46	44	67	Alone	17	19	—
White, non-Hispanic	40	43	16	Other	2	—	20
Hispanic	13	13	10				
Asian or Pacific Islander	1	1	—	<b>Primary caregiver</b>			
Other	1	<1	6	Parent	42	41	59
				Spouse	12	13	—
<b>HIV transmission group</b>				Other relative	16	16	13
Intravenous drug user:				Friend	15	16	1
Heterosexual male	37	42	—	Other	2	—	27
Heterosexual female	13	15	—	None	13	14	—
Homosexual or bisexual male	3	4	—				
				<b>Medicaid eligibility</b>			
Non-intravenous drug user:				Categorical	51	47	84
Homosexual or bisexual male	22	25	—	Institutional	49	53	16
Heterosexual male or female	7	7	—				
Parent at risk	10	—	87	<b>Status prior to enrollment</b>			
Hemophiliac or blood transfusion	3	3	8	Living in community	73	76	46
Unknown	4	4	5	Hospital	23	23	20
				Nursing home	<1	—	1
				Other	4	<1	32
<b>Primary diagnosis at enrollment</b>							
AIDS	81	84	59	<b>Length of enrollment in months<sup>4</sup></b>			
AIDS related complex	16	16	21	Mean	11.7	11.0	17.2
HIV positive under age 5	2	—	21	Median	9	8	19
<b>Functional capacity at enrollment</b>				<b>Age at enrollment</b>			
Complete help with activities of daily living (ADL) needed	28	26	40	Less than or equal to 19 years	11	—	100
Substantial help with ADL needed	33	33	34	20-29 years	16	18	—
Some help with ADL needed	40	41	26	30-39 years	51	58	—
				40-49 years	16	18	—
				50 years or over	6	7	—
				Median	35	35	1

<sup>1</sup>Enrolled from March 1, 1987, through February 28, 1989.

<sup>2</sup>21 years of age or over at enrollment.

<sup>3</sup>20 years of age or younger at enrollment.

<sup>4</sup>From time of enrollment until June 20, 1990. Twenty-three percent of the 675 clients enrolled by February 28, 1989, were still active as of June 20, 1990.

NOTES: Percents may not total 100 because of rounding. HIV is human immunodeficiency virus. AIDS is acquired immunodeficiency syndrome.

SOURCE: New Jersey Department of Human Services: Office of Home Care Programs, Client File.

Since the start of the program, there has been a trend toward lower level of care needs at the time of enrollment. Forty-two percent of clients enrolled during the first program year (1987-88) needed complete help with ADL at intake compared with 19 percent of cases admitted during the second year (1988-89). This finding may be related to an apparent trend toward program enrollment earlier in the course of illness as a result of increased outreach and to general improvements in the physical functioning of PWAs because of more effective medical treatments.

The average length of enrollment in the program was 11.7 months for clients enrolled during the first two program years and followed through June 1990 (23 percent of clients were still active as of that time). The median enrollment was 9 months. On average, children were enrolled for a longer period than adults were—a mean of 17 months compared with 11 months (Table 2). As might be expected, the primary reason for termination from the program was death, accounting for 87 percent of all terminations.

## Service utilization and total expenditures

The comprehensive nature of service coverage under ACCAP allows for examination of a relatively broad spectrum of health services utilization by a population of PWAs. It should be noted that an unknown number of ACCAP participants had other insurance coverage in addition to Medicaid; therefore, the data presented may not represent the complete utilization and cost experience while in the program. However, given the low-income and unemployment status of the clientele, Medicaid records probably include most health care utilization and costs for program enrollees. It should be kept in mind that HIV-related utilization prior to enrollment is not measured.

The service most commonly used by ACCAP participants is pharmacy. Medicaid claims indicate that 94 percent of the 538 enrollees represented in the files have paid claims for medications (Table 3). Other services used by a majority of program participants are: physician services (79 percent); outpatient hospital clinic (69 percent); home health agency<sup>3</sup> (58 percent); medical supplies and equipment (64 percent). Fifty-seven percent of clients used inpatient hospital services. Medical transportation services were utilized by 40 percent of the clients. Fewer than one in five had dental claims filed. The low rate of dental care utilization may reflect the difficulty in obtaining such services for HIV patients.

One-fifth or less of the population used waiver services other than case management. Personal care assistants were provided to 13 percent of ACCAP participants. Twenty percent used private duty nursing. Only 3 percent used medical day care services. Forty-two percent of the children (5 percent of the total

population) received family foster care services, and 17 percent utilized group home foster care. Low utilization of waiver services appears to reflect a combination of supply and other factors. At the time of the study, there was only one medical day care facility for PWAs in the entire State. Similarly, there was one five-bed group foster home.<sup>4</sup> Availability of home-based drug treatment is limited in part by payment rates that do not cover the cost of providing treatment and counseling on an individual basis. Other reasons for low utilization include the reluctance of treatment agencies to provide weekly doses of methadone and to send personnel to unsafe neighborhoods. During the early years of the program, many home care agencies did not offer personal care assistants because of low payment; shortages of personnel also reduced utilization. In addition, help with personal care often may be provided by family members rather than by paid helpers.

The total cost of claims for the first 23 months of the program was \$10,899,906.<sup>5</sup> Fifty percent of all program expenditures were for inpatient hospital services (Table 3). However, one-half of the inpatient costs were attributed to only 18 percent of all participants. Medications accounted for 16 percent of program costs. Hospital outpatient services were 4 percent of total costs. Physician services were 2 percent of total costs, reflecting low Medicaid payment for physician charges.

Inpatient hospital services accounted for 70 percent of medical care costs, defined as the total of inpatient, outpatient, physician, and pharmacy services. Studies of PWAs in California, San Francisco, and Boston indicate that inpatient costs may range from 86 percent to 89 percent of total medical care costs (Scitovsky et al., 1989). Based on Hellinger's (1990) estimates, inpatient services comprise 79 percent of lifetime medical care costs. It is possible that the lower proportion of expenditures spent on inpatient care for the ACCAP population may be a result of an underestimation of costs as more than one-half the clients had not yet used inpatient services during the period of observation. In addition, the inpatient component of medical care costs for HIV may have declined since the time many of the above studies were conducted in the mid-1980s (Hellinger, 1988; Seage et al., 1990).

Waiver services totaled \$1,756,979 and accounted for 16 percent of all expenditures. The combined costs of all other categories of service such as transportation, home health agency, laboratory, and medical supplies accounted for less than one-sixth of total expenditures. The total cost of non-inpatient services was \$5,406,000 over the 23-month period.

Examination of waiver services indicates that case-management services were 3 percent of total

<sup>3</sup>Home health agency services refer to home health services covered by New Jersey's regular Medicaid plan. These include such services as visiting nurses, home health aides, and rehabilitation therapy.

<sup>4</sup>As of 1991, there were two medical day care facilities and a total of five group homes for children.

<sup>5</sup>All reported expenditures are based on Medicaid payments rather than on charges and are unadjusted for inflation. The cost figures presented underestimate total actual costs for the observed 23-month period because of the exclusion of cases enrolled after November 30, 1988, from the computer tape provided.



Table 3

Service utilization and program expenditures of the New Jersey AIDS-specific Medicaid waiver program<sup>1</sup>

Service	Percent of total program expenditures <sup>2</sup> (\$10,899,906)	Average expenditures per person (n = 538)	Percent of enrollees using service <sup>3</sup> (n = 538)	Average paid per user of each service
Total average cost per person	—	\$20,260	—	—
Waivered services	16	\$3,266	100	—
Case management	3	548	92	\$548
Private duty nursing	8	1,715	20	8,465
Personal care assistants	3	443	13	3,501
Medical day care	<1	70	3	2,366
Home drug abuse treatment	<1	9	2	257
Family-based foster care	<1	43	5	789
Group home foster care	2	438	2	26,165
State plan services	84	\$16,994	98	—
Pharmacy	16	3,280	94	3,481
Physician	2	340	79	429
Inpatient hospital	50	10,212	57	18,013
Outpatient hospital	4	733	69	1,066
Independent clinic	<1	90	20	442
Home health agency (visiting nurse, physical therapy, etc.)	6	1,231	58	2,117
Medical supplies and equipment	4	860	64	1,349
Transportation	1	179	40	451
Independent laboratory	<1	13	20	67
Dental	<1	37	18	206
Optometric	<1	5	13	36
Optical appliance	<1	3	10	33
Durable medical equipment	<1	3	1	305
Psychology	<1	8	1	683
Podiatry	<1	<1	1	37
Chiropractor	<1	1	<1	225

<sup>1</sup>Based on claims for services provided March 1, 1987, through January 1, 1989, for clients enrolled by November 30, 1988.

<sup>2</sup>Includes both waiver and State plan expenditures for program participants. Percents may not total 100 because of rounding.

<sup>3</sup>Percents do not total 100 because of multiple response categories.

NOTES: AIDS is acquired immunodeficiency syndrome. (n = 538) is number of people in the population.

SOURCE: New Jersey State Department of Human Services, Division of Budget and Accounting, Bureau of Data Processing: Data from Medicaid claims file.

expenditures. Personal care assistants also accounted for 3 percent of costs, and foster care accounted for 2 percent. Medical day care and home drug abuse treatment were each less than 1 percent of total program expenditures. The most expensive waiver service was private duty nursing, accounting for 8 percent of total costs. A further breakdown of private duty nursing costs indicates that 57 percent of the total cost of private duty nursing was for services provided by licensed practical nurses (LPNs) and 43 percent was for services provided by a registered nurse (RN). Seventy-eight percent of those using private duty nursing received some of this care from LPNs compared with 53 percent receiving some care from RNs. Interviews with case managers indicated that the greater use of LPNs may be a reflection of shortages of home health aides.

Costs per user for group home foster care were relatively high. This service accounted for 13 percent of the \$1,756,979 spent for waiver services but was used by only 9 (1.7 percent) of the 538 enrollees represented in the claims file. Low utilization is due in part to the small supply of group home beds. Costs for the 28 children in family foster homes were 1 percent of total waiver services costs. There is evidence that care for

children with HIV is more costly than for adults in part because of the difficulty in finding foster homes for these children, resulting in medically unnecessary use of inpatient services (Hegarty et al., 1988; Kemper and Forsyth, 1988; Scitovsky, 1990). ACCAP data suggest that although group homes may be less expensive than long-term institutionalization in acute care facilities, expenditures for children with HIV may remain disproportionately high because of the particular problems of developing community-based alternatives for the many children whose parents and families also have the disease.

### Average expenditures

Table 3 presents average expenditures per enrollee and per user of each service. The average total amount paid per client for the first 23 months of the program (1987-89) was \$20,260. There was no difference between AIDS and ARC cases in the average total expenditure per person. The average amount paid per person for waiver services over the entire enrollment period was \$3,266. State plan services cost an average \$16,994 per person. Excluding inpatient services, average total expenditures per client were about \$10,000.

The average total cost per person-month was about \$2,400.<sup>6</sup> Waiver services average \$388 per person-month. Inpatient services were \$1,212 per person-month and all other State plan services averaged \$805 per person-month for a total of \$2,017 per person-month for State plan services. Home care costs (waiver services, medical supplies and equipment, medical transportation, and home health agency services) averaged \$18 a day per person.

Scitovsky (1988) estimates that in recent years, lifetime medical care costs have ranged between \$50,000 and \$60,000 per PWA. Based on an average 12- to 18-month survival time of PWAs from time of diagnosis (Harris, 1990; Hellinger, 1990; Seage et al., 1990), Scitovsky's figures yield an average monthly cost ranging from about \$2,800 to \$5,000. Hellinger (1990) estimates lifetime expenditures, depending on life expectancy, of \$60,000-\$90,000 per patient for inpatient care, outpatient services, and pharmacy, which translates to \$5,000 per person per month for these services. Among adult waiver clients diagnosed with full-blown AIDS at enrollment, average expenditures per person-month were \$3,251 for all services. The lower average found for the waiver program compared with Hellinger's estimate appears to be largely a result of Hellinger's assumption of higher inpatient charges per day. Applying Hellinger's per diem rate of \$1,000 in inpatient charges to ACCAP data, total monthly waiver program expenditures per person are about \$500 higher than Hellinger's.

## Hospital utilization and costs

Average length of stay per admission for all hospitalized ACCAP clients was 14.8 days. The median number of days was 9, with a maximum of 370 days. Excluding two inpatient outliers who had stays of 187 and 370 days, respectively, the average length of stay per ACCAP admission was 14.0 days. The average cost per admission was \$7,960<sup>7</sup> during 1987-89. Clients diagnosed with ARC at enrollment had somewhat lower lengths of stay per admission than did patients with full-blown AIDS, but there were no differences in the number of admissions, total inpatient days, or total inpatient expenditures.

In order to make comparisons with other surveys, the data for waiver participants were analyzed for hospitalized clients with a diagnosis of AIDS at enrollment (i.e., excluding cases of ARC). Like other

studies, a single year of observation was used.<sup>8</sup> It should be noted that both the waiver and survey data are for hospital users and do not reflect population-based utilization patterns.

Among hospitalized adults and children with a diagnosis of full-blown AIDS, the total annual inpatient cost per waiver patient was \$16,938 during 1988. Nationwide in 1987, the average cost across all age groups was \$17,910 per patient; in the Northeast, the average was \$20,661 (Andrulis, Weslowski, and Gage, 1989).

The average length of stay per admission for ACCAP clients with AIDS was 15.8 days. Length of stay per admission for PWAs in hospitals in the Northeastern United States was 20.8 days, and the nationwide average was 16.8 days (Andrulis, Weslowski, and Gage, 1989). Another study based on data from the National Hospital Discharge Survey found that PWAs had an average length of stay of 15.9 days per admission in 1987 (Moien and Kozak, 1989).

The Andrulis survey reports that during 1987, the average annual number of hospital days per patient was 26.3 nationwide and 31.4 in the Northeast (Andrulis, Weslowski, and Gage, 1989). Annual hospital utilization among ACCAP clients averaged a total of 31.7 days in 1988. There were 2.0 admissions per hospitalized ACCAP patient compared with 1.6 admissions among hospitals nationwide and 1.5 in the Northeast during the 12-month period.

Hospital utilization and expenditures among ACCAP clients appear to be lower than among New Jersey's general and Medicaid PWA populations. A State Health Department survey of all 1987 hospital discharges for AIDS patients 13 years of age or over reports that average length of stay per admission was 18.46 days for all hospitalized PWAs and 18.37 days for Medicaid discharges (Coye, Conviser, and Grant, 1990). Statewide, there were 1.95 admissions per hospitalized PWA and a total of 36.25 days per patient for the year; Medicaid patients statewide average 2.44 admissions and 44.84 days, higher than all other payer groups. Among hospitalized ACCAP clients 13 years of age or over diagnosed with AIDS at enrollment, average length of stay per admission was 16.29 days in 1988 (Table 4). Hospitalized waiver clients averaged 1.90 admissions and 31.05 days for the year. Inpatient costs were also lower for waiver participants. The cost per admission for hospitalized waiver clients was \$7,843, and the average annual inpatient cost per patient was \$14,902. Statewide, the cost per admission was \$10,929, and the total annual cost per year was \$21,269 per person; costs for Medicaid patients were \$10,156 per admission and totaled \$24,780 per patient for the year.

Comparison of utilization and cost data must be made cautiously. They are based on single years of observation, and a given year may not be representative

<sup>6</sup>In order to adjust for length of time in the program, costs per month are based on the actual number of months each of the 538 clients in the claims file was enrolled in the program during the 23-month period covered by the claims data. This yields a total of 4,532 person-months.

<sup>7</sup>Of the inpatient claims, 8 percent were for procedures that did not involve an overnight stay. These claims are excluded from the hospital utilization data but are included in inpatient cost figures. The single-day claims accounted for 1 percent of all inpatient expenditures and 11 percent of the average cost of inpatient services per user.

<sup>8</sup>In order to measure complete experience, 1988 was used rather than the first waiver year, which is probably unrepresentative because of startup factors. Note that the figures from all sources are not person-years, rather, they measure hospitalizations that occurred during a given 12-month period.

of overall trends. In addition, it is possible that the lower utilization noted for waiver clients in 1988 compared with that for PWAs in 1987 may be affected by a secular trend toward decreased lengths of stay observed for earlier years of the epidemic (Hellinger, 1990; Seage et al., 1990).

Regional differences may reflect variation in both case mix and utilization patterns. However, given the high proportions of IVUDs and minorities in the waiver population and the tendency to enroll people in later stages of the disease, one would expect increased utilization and costs among waiver clients. New Jersey's AIDS population is similar to that elsewhere in the Northeast, whereas other regions have higher proportions of non-IVDU homosexual PWAs who may need less inpatient care. The longer lengths of stay and lower number of admissions found in the Northeast compared with the rest of the Nation are probably heavily influenced by the experience of New York City, where hospital overcrowding and homelessness have resulted in this pattern of hospital "gridlock" (Kotelchuck, 1989).

ACCAP data include only admissions charged to Medicaid during enrollment in the program, while the national survey includes all payer sources. Expenditures may vary from State to State because of differences in payment and regulatory structures. The average per diem hospital cost in 1987 for PWAs in New Jersey (Coye, Conviser, and Grant, 1990) was lower than the daily costs found in the Andrulis survey, nationwide and in the Northeast. However, when the data are adjusted for the daily cost difference, inpatient expenditures for waiver clients are approximately equal to those of patients in the Northeast, and costs for the New Jersey general and Medicaid PWA populations are higher.

Most importantly, hospitalized waiver clients appear to have used less inpatient services than New Jersey's hospitalized PWA population. This difference is probably not a result of better financial access to inpatient care for waiver clients. New Jersey's hospital uncompensated care pool helps finance inpatient care to uninsured PWAs. In addition, utilization differences for waiver clients were particularly striking compared with those for New Jersey Medicaid patients. The average length of stay for admissions among waiver

clients was lower by 2.1 days. Annual inpatient use for waiver participants averaged almost 14 fewer hospital days per person compared with the total Medicaid population of hospitalized PWAs; this difference appears to be greater than the observed secular trend toward decreasing utilization (Andrulis, Weslowski, and Gage, 1989). The similarity of waiver clients to the general New Jersey PWA population in terms of risk group and demographic characteristics suggest that the findings are not influenced by these factors. Lower inpatient utilization by waiver clients is probably a result of either the effect of the waiver program or of such client selection factors as the availability of housing and social support. The services and support provided by the waiver may also make it possible for families to care for their relatives with AIDS at home. Further research is needed to determine if inpatient utilization is also lower on a populationwide basis in addition to user-based comparisons.

As noted previously, average monthly expenditures for waiver clients may be lower than the available estimates because of differences in the assumed cost of various components of medical care. However, the ACCAP data also include costs of home care services not typically represented in many estimates that are limited to medical care expenditures. Given the rudimentary stage of AIDS health services research, the lifetime cost estimates by Scitovsky and Hellinger are based on evidence acquired across different empirical studies and may be considered as "best guesses." Cost comparisons should be viewed only as suggestive. The evidence from the hospital utilization analysis suggests that because waiver participants appear to use less inpatient care than other PWAs in New Jersey, the potential exists for reducing the most expensive component of AIDS care. More research is needed to directly examine the issue of the relative cost of the waiver.

## High-cost clients

In order to better understand factors influencing utilization patterns and costs, ACCAP clients whose total costs greatly exceeded those of others in the program were examined. This analysis revealed that a relatively small number of clients were responsible for a

Table 4

### Comparison of average inpatient utilization and expenditures, by New Jersey waiver clients and acquired immunodeficiency syndrome (AIDS) patients statewide

Item	Waiver patients, 1988 <sup>1</sup>		New Jersey AIDS patients, 1987 <sup>2</sup>		New Jersey Medicaid patients, 1987 <sup>2</sup>	
	Number	Average	Number	Average	Number	Average
Admissions per patient	179	1.90	1,619	1.95	391	2.44
Total days per patient	179	31.05	1,619	36.25	391	44.84
Length of stay per admission	341	16.29	3,153	18.46	853	18.37
Cost per admission	341	\$7,843	3,153	\$10,929	853	\$10,156
Total cost per patient	179	\$14,902	1,619	\$21,269	391	\$24,780

<sup>1</sup>Based on hospitalized enrollees 13 years of age or over who had a diagnosis of full-blown AIDS at enrollment.

<sup>2</sup>Based on statewide hospital discharge records of persons 13 years or over with AIDS.

SOURCES: Waiver data are based on data provided by the New Jersey Department of Human Services, Division of Budget and Accounting, Bureau of Data Processing; statewide AIDS patients and Medicaid data are from Coyle et al. (1990).

large proportion of program payments. The 50 clients whose total costs were \$50,000 or more (outliers) represented 9 percent of the ACCAP cases in the claims file but accounted for 35 percent of all expenditures.

Utilization and costs of services by the outliers tended to be disproportionately high for almost all categories of services. This finding was not due to incomplete utilization experience for the non-outliers, because the cost group differences were maintained within both active cases and cases terminated due to death. Furthermore, outliers were more likely to be active cases—70 percent versus 49 percent of the non-outliers. For example, 92 percent of the outlier decedents received inpatient care compared with 60 percent of the non-outliers who had died. Ninety-two percent of the outlier decedents used home health agency services compared with 60 percent of the non-outlier decedents.

Cost differences were particularly great for the more intensive services of inpatient care, private duty nursing, durable medical equipment, and other medical supplies and equipment. In addition, the absolute costs for the outliers were much greater across all service categories, reflecting perhaps a sicker population. The average cost per user of inpatient services was about \$50,000 for both living and deceased outliers compared with \$11,000 for non-outliers who were still alive and \$13,800 for those who had died. Private duty nursing care averaged almost \$6,500 per client for the outlier decedents compared with about \$2,000 per client among the non-outlier decedents. The average total cost per client for the living and deceased outliers was \$76,260 and \$79,730, respectively, versus \$14,000 and \$15,290, respectively, for living and deceased non-outliers. Thus, a small number of cases accounted for a disproportionate amount of total costs and expenditures for the most intensive services.

A profile of the background characteristics of the high-cost clients indicates that outliers were significantly more likely to be women—40 percent of the outliers compared with 24 percent of the non-outliers (women accounted for 26 percent of the total client population).<sup>9</sup> Women with a history of intravenous drug use were also over-represented among the outliers—25 percent of the outliers versus 13 percent of the non-outliers. There were more than twice as many children in the outlier group compared with the lower cost group (24 percent versus 11 percent). The high-cost group tended to include more persons who were not white (74 percent) compared with the proportion in the remaining program population (62 percent). There was a significantly greater proportion of clients categorically eligible for Medicaid among the outlier group (66 percent) compared with the non-outliers (53 percent). High-cost clients were less likely to be cared for by a spouse; 13 percent of the lower cost clients relied on their spouses as caregivers, similar to the frequency in the entire enrollment, compared with only 4 percent of the outliers. However, the outliers were no more likely than lower cost clients

to live alone. Seventy-four percent of clients with costs greater than \$50,000 required substantial or complete ADL assistance compared with 59 percent of the lower cost clients; however, this difference was not statistically significant.

## Access to services

In order to assess problems with the delivery of services and unmet needs, personal interviews with case managers and a random sample of clients were conducted. Questions were asked about specific health and social services needed by clients, the seriousness of unmet needs for these services, and particular problems related to the delivery of services.<sup>10</sup>

At least one-half of the 46 interviewed case managers reported that most of their clients required the following health services (even if they were already receiving them): medical care, visiting nurses, medical supplies and equipment, medications, and medical transportation (Table 5). Other frequently cited health service needs included dental care and help administering medications. A majority of case managers also said that at least some of their clients needed private duty nursing, personal care assistance, housekeeping and food preparation, methadone treatment, and mental health services. The large majority of interviewed clients also said they needed transportation services, medical supplies and equipment, medical care, dental care, visiting nurses, and help getting medications (Table 6).

According to both case managers and clients, the most readily available health services were medical care, visiting nurses, and medications (Tables 6 and 7). According to HCFA estimates, 75 percent of HIV medication expenditures are paid for out of pocket (Scitovsky, 1988). Thus, Medicaid coverage of these often expensive therapies serves a great need of PWAs.

Unmet needs were most frequently related to the availability of home health care services intended to help clients with activities of daily living. According to case managers, general shortages of home health services were exacerbated for HIV clients. Very frequent shortages of personal care attendants (home health aides and personal care assistants) were noted by at least 70 percent of the case managers (Table 7). Three-quarters of the case managers whose clients required personal care services said that unmet needs in this area were somewhat or very serious. Forty-three percent of the case managers said they often encountered problems obtaining adequate service coverage for clients needing private duty nursing because of a general shortage of nurses. Similar shortages of nursing and other home health personnel for AIDS patients have been noted in other areas of the country (Howell et al., 1989; Mor, Piette, and

<sup>9</sup>Reports of significance are at the  $p \leq .05$  level based on the chi-squared test.

<sup>10</sup>Case managers were asked: "About how many of your clients need service: Most, some, a few, or none?" "How often do you encounter the following service delivery problems with your ACCAP clients: Very often, sometimes, once in a while, or hardly ever or never?" "Are the unmet service needs in this area a very serious problem, somewhat serious, not at all serious, or aren't there any problems?"

**Table 5**

**Percent distribution of case manager reports of service needs: New Jersey AIDS-specific Medicaid waiver program**

Service	Most clients need	Some clients need	A few clients need	No clients need
	Percent distribution of responses			
General medical care	100	—	—	—
Specialty medical care	54	37	9	—
Medical day care	15	11	22	52
Private duty nursing	11	39	20	30
Visiting or public health nurse	59	30	—	11
Dental care	46	22	17	15
Housekeeping	22	28	17	33
Food preparation	20	36	13	31
Personal care	28	33	11	28
Emergency medical transportation	28	22	26	24
Other medical transportation	48	28	7	17
Help getting medications	83	9	2	7
Administering medications	41	20	26	13
Intravenous therapy	11	20	48	22
Aerosol pentamidine	22	26	20	33
Medical supplies and equipment	59	33	7	2
Methadone treatment <sup>1</sup>	14	36	25	25
Other drug or alcohol treatment <sup>1</sup>	14	21	29	36
Psychological or mental health	28	19	26	28
Rehabilitation (physical or speech therapy, etc.)	22	26	33	20
A "buddy"	22	24	20	35
More social contact	46	26	15	13
Supplemental Security Income, welfare, unemployment, or other public benefits	85	11	—	4
Other financial help	47	22	13	18
Foster care <sup>2</sup>	58	16	—	26
Emergency housing or shelter	6	13	28	52
Adequate permanent housing	13	24	22	41
Legal advice	17	28	30	24
Child care <sup>1</sup>	—	18	50	32
Food (financial assistance, special diet, etc.)	20	24	24	33

<sup>1</sup>Based on responses from 28 case managers of adult clients.

<sup>2</sup>Based on responses from 19 case managers of children.

NOTES: Percents may not total 100 because of rounding. AIDS is acquired immunodeficiency syndrome.

SOURCE: In-person interviews with 46 New Jersey Medicaid waiver case managers.

Fleishman, 1989; Preston, Andrews, and Howell, 1989). The effectiveness of AIDS education in reducing provider unwillingness to work with PWAs, particularly among personal care attendants, was noted by a number of ACCAP case managers and home health agency administrators.

Fifty-three percent of the ACCAP case managers said that a general shortage of medical transportation was a very frequent problem. Seventy percent of those with clients requiring this service considered the unmet needs in this area to be very or somewhat serious because of the frequent need for physician visits among PWAs and of the distance of providers from clients' residences. A number of case managers remarked that services in general were more difficult to obtain in rural areas, where home care providers had to travel long distances to clients' homes.

Unmet mental health needs were considered a serious problem by 58 percent of the case managers with clients requiring such services. Although 57 percent of the case managers who had clients needing drug rehabilitation services noted that there were no problems obtaining methadone maintenance services, another 38 percent said that unmet needs in this area were serious. Unmet needs for other types of drug and alcohol treatment

were more widespread; 56 percent of the case managers with clients needing these services said that the unmet needs were serious. The unavailability of mental health and drug rehabilitation services, particularly those targeted to PWAs, is a serious problem throughout the country (Andrews, Welch, and Howell, 1989; U.S. General Accounting Office, 1989; Howell et al., 1989; Preston, Andrews, and Howell, 1989).

Although specific delivery problems were noted, both case managers and clients saw the program as successful in providing access to services in general. Ninety-seven percent of the interviewed clients expressed satisfaction with the program. When asked why they were satisfied, 10 clients (31 percent) said the reason was financial coverage of health services. Thirteen participants (41 percent) also responded that the program provided them with needed services. When asked to evaluate the program's performance, 46 percent of the case managers considered providing access to needed services to be a major reason for the program's success. One-third of the case managers also mentioned the financial benefits as an important factor.

When asked for their recommendations on improving the program, most case managers focused on administrative and access issues. Frequently mentioned

**Table 6**  
**Number of interviewed enrollees reporting service needs: New Jersey AIDS-specific Medicaid waiver program**

Service	Needs service		Gets service	
	No	Yes	No	Yes
	Number of enrollees			
Transportation to hospital, clinic, or doctor	9	24	3	21
Visiting nurse	14	19	1	18
Private or special duty nurse	30	2	—	2
Homemaker services	26	7	1	6
Medical supplies or equipment	11	22	1	21
Methadone treatment	27	6	—	6
Other drug or alcohol treatment	32	1	—	1
Rehabilitation therapy	24	7	6	1
Medical care	2	31	1	30
Dental care	8	25	7	18
Food preparation or delivery	19	14	2	12
Help with dressing or washing	28	5	1	4
Help buying, picking up, or taking medications	16	17	2	15
Aerosol pentamidine	15	18	—	18
Psychological counseling	25	8	3	6
A "buddy"	21	10	4	6
More contact with other people	20	12	4	6
Supplemental Security Income, welfare, unemployment, or other public benefits	2	30	2	28
Other financial help	14	18	17	1
Housing	18	15	7	8
Legal help	29	4	4	—
Child care	28	3	—	3
Food	18	15	12	3

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: In-person interviews with 33 New Jersey Medicaid waiver clients.

**Table 7**  
**Percent distribution of case manager reports of frequency of service delivery problems: New Jersey AIDS-specific Medicaid waiver program<sup>1</sup>**

Service problem	Frequency of problem			
	Very often	Sometimes	Once in a while	Hardly ever or never
	Percent distribution of responses			
Turnover of private duty nurses (28)	32	29	7	32
Hard to cover nursing shifts (e.g., weekends)(28)	36	29	18	18
General shortage of private duty nurses (28)	43	18	32	7
General shortage of visiting nurses (40)	5	13	5	77
Turnover of home health aides (31)	32	19	29	19
Hard to cover home health aide shifts (34)	56	21	12	12
General shortage of home health aides (37)	73	19	5	3
Turnover of personal care assistants (12)	42	50	—	8
Hard to cover personal care assistant shifts (12)	33	50	8	8
General shortage of personal care assistants (20)	70	25	5	—
Poor training of home health workers (42)	9	21	14	55
Providers won't deal with AIDS clients (46)	24	26	9	41
Providers won't go to bad neighborhoods (46)	17	11	13	59
Not enough Medicaid approved providers (46)	24	26	7	43
Problem getting medical care (46)	9	17	7	67
Problem getting dental care (40)	35	17	8	40
Lack of psychiatric inpatient service (31)	26	16	3	55
Problem getting medications (46)	2	15	4	78
Meals On Wheels unavailable (23)	39	17	4	39
Hard to get home delivery of methadone (19)	16	21	16	47
Hard to get other drug or alcohol treatment (21)	24	14	9	52
Medical transportation doesn't show up or is late (36)	39	14	11	36
Lack of emergency medical transportation (36)	31	6	11	53
General shortage of medical transportation (40)	53	5	10	33
Shortage of home-based rehabilitation services (41)	7	15	5	73

<sup>1</sup> Percents presented are based only on data from those case managers with relevant experience. The number of case managers responding to each specific item is noted in parentheses. Percents may not total 100 because of rounding.

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: In-person interviews with 46 New Jersey Medicaid waiver case managers.

changes included simplification of the enrollment process, increasing the number of Medicaid-approved providers, increasing provider payment rates in order to address supply problems, and AIDS education for home health workers. In general, case managers felt that the range of services covered was adequate but service shortages created the most serious problems. This assessment appears to be shared by clients; their most frequently mentioned reasons for unmet health care needs were related to problems obtaining services, particularly transportation and physical therapy.

Although both case managers and clients noted certain problems with the delivery of some health services, the most serious unmet needs were related to social and economic conditions. Thirty-seven percent of the interviewed case managers said that most or some of their clients had inadequate permanent housing. Nineteen percent said that at least some of their clients had required emergency housing. Each of these problems was rated as very serious by more than one-half of the case managers who reported any clients with needs in these areas. Seventeen of the 33 clients interviewed said they had financial problems. Eighty-five percent of the case managers said that most of their clients received Supplemental Security Income or other public benefits. However, more than two-thirds of the case managers also said that at least some of their clients needed more financial help than was provided by benefits. This help was needed mainly for housing and other basic living expenses including food.

Case managers said that social isolation of PWAs was also a problem. Forty-six percent said that most of their clients needed more social contact, and another 26 percent said that some of their clients experienced this problem. The severity of unmet needs in this area was rated as somewhat or very serious by 70 percent of the case managers interviewed. Expanded availability of medical day care could help address this area of need for ambulant PWAs in addition to providing the medical, nutritional, and mental health services offered by day care programs.

Unmet social needs were also found for children. A number of case managers for children noted the unavailability of educational and day care services for children with HIV. Although most adult clients did not have children, the need for child care assistance was rated as serious by 13 of the 22 case managers who had clients requiring help in this area.

## **Role of case management**

The nature of health service needs noted by clients and case managers suggests that a critical factor in assuring the quality of home care for PWAs is the presence of an advocate who works to secure services that are in short supply or otherwise difficult to obtain. ACCAP case managers served the role of negotiators of the health care system on behalf of their clients (Crystal, Merzel, and Kurland, 1990). Evidence of their success is found in client satisfaction with case management services. More than 90 percent of the

interviewed clients said that the case manager made it easier for them to get needed services. When asked what they found most helpful about the program, 13 clients (39 percent) noted the help provided by case managers in obtaining services and 7 (21 percent) mentioned the social and emotional support provided by the case manager.

The ability of case managers to respond to clients' needs may be due in part to program requirements to monitor clients on a monthly basis and to the relatively low caseloads of ACCAP case managers. Program procedures limit adult caseloads to no more than 35 ACCAP clients. Caseloads in other case-management programs for PWAs are frequently much higher, and capacity cannot meet demand (Howell et al., 1989; Mor, Piette, and Fleischman, 1989; Preston, Andrews, and Howell, 1989; Vladeck, 1989). In addition, the ability to provide comprehensive case management under the structure of a single program may help avoid the fragmentation of case-management services found elsewhere (Andrews, Welsh, and Howell, 1989; Howell et al., 1989).

Review of case records and interviews indicated that case managers were closely involved in the planning and coordination of health services. They also spent extensive amounts of time speaking directly by telephone to providers in order to ensure actual delivery of services ordered. Although case managers were found to deal with social service needs of their clients, they tended to focus their activities on health care. Case record reviews and interviews indicated that case managers had much more contact with health care providers than with social service agencies or community organizations. Three-quarters of the case managers reported that they spent a greater amount of time arranging for health services than for social services. These findings are attributed to the nursing background of most case managers (75 percent have nursing degrees), the fact that most case-management providers are home health agencies, and the general nature of the waiver program that provides payment for health-related services. More detailed description of ACCAP case-management activities is presented elsewhere (Crystal, Merzel, and Kurland, 1990).

## **Conclusions**

As people with HIV live longer and function better because of improvements in medical treatment, the Medicaid home and community-based waiver is an important policy mechanism for providing long-term HIV care. As the Nation's first AIDS waiver program, the New Jersey program evolved over time as knowledge and experience increased concerning delivering community-based services to people with AIDS. The experience in New Jersey demonstrates that waivers can be a successful means of providing both the broad range of health services and the financial coverage for health care needed by persons with HIV. The extension of program availability to people with ARC and to symptomatic HIV-positive children is an innovative measure. These two groups are often

overlooked in AIDS programs and entitlements, even though their physical and financial needs are frequently similar to those with full-blown AIDS.

The waiver provides important benefits that are unavailable through standard Medicaid programs. First, it expands financial eligibility, providing access to both waiver and State plan services for those who would not otherwise be covered by Medicaid; one-half of the New Jersey AIDS waiver population is entitled only through the waiver. Second, case management is, perhaps, one of the most important services available through the waiver. The multifarious medical and health service needs of PWAs require much expertise and coordination to assure access to and quality of care. Case managers provide both material and social support to clients at a time of great physical and emotional vulnerability. Although case managers were less involved in coordinating social services, their role extended beyond that of managing health and home care services into helping clients and their families deal with their social and emotional needs. Other waiver services, such as private duty nursing and personal care assistants, provide important specialized services to segments of the population requiring them. HIV-specific medical day care is an innovative service that is worthy of expansion in order to make it accessible to greater numbers of PWAs.

Total expenditures for the program were well below the federally established ceiling. Expenditures, however, could increase if all needed services were available and delivered. As in other studies of health care utilization, a small number of clients accounted for a disproportionate amount of total expenditures. Although PWAs need some inpatient services irrespective of the availability of other services, waiver participants appear to have lower lengths of stay and to have used less hospital acute care compared with the general New Jersey PWA and Medicaid PWA inpatient populations. Hospital costs also appear to be lower for waiver clients than for other New Jersey PWAs. These findings are suggestive of the additional research needed to determine if the waiver can reduce overall Medicaid expenditures for HIV.

The experience of the New Jersey program suggests that home and community-based health care can be provided to a heterogeneous population of PWAs, given the availability of financial resources and formal and informal support services. A majority of those enrolled in the program were minorities and/or had a history of intravenous drug use. Most of those enrolled in the program were able to depend on their families to provide an important source of informal care. We emphasize, however, that there are significant numbers of PWAs, particularly among the homeless, whose needs cannot be served by traditional home care arrangements that are geared toward providing services in an individual or family home setting. Consequently, access to services for such populations is severely limited. Areas for further research include assessment of the ability of home care programs to address the special needs of women, children, IVUDs, and caregivers of PWAs.

The scope and severity of the social and economic problems encountered by ACCAP clients have important implications for the development of community-based care models that give attention to the full range of needs of PWAs. The most serious unmet needs of program participants were related to areas that are beyond the parameters of the traditional home care model. There is increasing recognition that the lack of appropriate and affordable housing is one of the most severe problems facing persons with HIV, impeding the ability to utilize home care services (U.S. General Accounting Office, 1989; Mor, Piette, and Fleishman, 1989; Vladeck, 1989). Other waiver States have also found housing needs to be a pressing problem, and some have recommended adding bed and board in residential facilities as a covered service (Jacobson, Lindsey, and Pascal, 1989).

Although many of these issues cannot be resolved within the health services sector alone, they need to be recognized as vital elements of HIV home care in order to develop more comprehensive models. This underscores the importance of developing multidisciplinary case-management systems and health care teams that can identify and begin to address the various health and social service needs among diverse groups of PWAs (Mor, Piette, and Fleishman, 1989; Volberding, 1989).

The Medicaid waiver is an innovative instrument for dealing with the long-term care needs of PWAs. The waiver addresses several factors that are critical elements in the delivery of home- and community-based health care to persons with HIV. First, it provides financial access to a wide range of health services, which is necessary in order to comprehensively address the multiple medical and health care needs of PWAs. Secondly, the waiver is a means of providing the comprehensive case management needed to help obtain services that financial access alone cannot secure. Shortages in the supply of home care services and workers were the primary reason for unmet health care needs found among ACCAP participants. Case managers functioning in the context of broad responsibility for planning and obtaining services for their clients can be effective in improving access to services. Although these benefits are important, it is clear that Medicaid waivers are but one element in a complex network of broad-based policy and service delivery mechanisms required to address fully the multifaceted health and social needs of persons with HIV.

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