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# Home-Care Use and Expenditures Among Medicaid Beneficiaries with AIDS

Usha Sambamoorthi, Ph.D., Sara R. Collins, Ph.D., Stephen Crystal, Ph.D., and James Walkup, Ph.D.

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*This article compares the use and cost of home-care services among traditional Medicaid recipients with acquired immunodeficiency syndrome (AIDS) and among participants in a statewide Human Immunodeficiency Virus (HIV)/AIDS-specific home and community-based Medicaid waiver program in New Jersey, using Medicaid claims and AIDS surveillance data. Waiver program participation appears to mitigate racial and risk group differences in the probability of home-care use. However, the program's successes are confined to its enrollees of which subgroups of the AIDS population are underrepresented. Our findings suggest the need to expand access to home-care programs to racial minorities and injection drug users (IDUs) with HIV/AIDS.*

## INTRODUCTION

The recent introduction of highly active antiretroviral treatment of HIV disease combined with aggressive use of prophylactic therapies for opportunistic infections continues to shift the nature of HIV/AIDS treatment from acute care to chronic management (Freedberg et al., 1998; Fogarty et al., 1997; Ettner and Weissman, 1994). In addition, advances in medical treatment have made it increasingly possible for AIDS patients to be cared for in their homes

(Buchanan, 1995/1996). These technological changes in AIDS medical care, coupled with a desire on the part of Medicaid programs, the primary payers of AIDS-related services,<sup>1</sup> simultaneously to reduce the cost of AIDS care and improve the quality of life of AIDS patients, have generated greater interest in treating these patients in non-institutional settings and in managed care arrangements (Aseltine, Cloutier, and Smith, 1995). Indeed, research has shown that the proportion of persons with AIDS (PWAs) who die at home has grown throughout the course of the epidemic (Kelly, Chu, and Buehler, 1993).

However, there is evidence that the use of non-institutional services, particularly in the last few months of life, has been highest among white males and that the groups which have seen the largest recent increases in HIV infection and AIDS—females, IDUs, racial minorities, and people with unstable housing arrangements—are more likely to use inpatient services (Bonuck and Arno, 1997; Fleishman, Mor, and Laliberte, 1995; Kelly, Chu, and Buehler, 1993). Access to home and community-based services has been shown to reduce inpatient utilization (Cohn, Klein, and Weinstein, 1996; Cunningham et al., 1996). Using a research database linking New Jersey AIDS Registry, Medicaid claims, and other administrative files, Crystal, LoSasso, and Sambamoorthi (1999)

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<sup>1</sup> In 1997, combined State and Federal expenditures on AIDS care in the Medicaid program totaled \$3.3 billion, spending by Medicare on AIDS totaled \$1.3 billion, and combined State and Federal spending for the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act was \$1.2 billion (Graydon and Gordon, 1999).

reported that participation in Medicaid programs offering case management and home-care services reduces length of hospital stays and lowers probability of death while hospitalized. Evidence from Master et al. (1996) suggests that use of home-care services may have had an impact on reducing inpatient utilization and costs.

Medicaid's 1915c home and community-based waiver program for AIDS patients is a mechanism by which States can broaden the use of home-care services. Available since 1985, AIDS-specific waivers are currently operating in 16 States.<sup>2</sup> Yet, there is little published research on the types of beneficiaries enrolled in the programs and on socioeconomic and risk group differences in service use and expenditures (Schore et al., 1997; Anderson and Mitchell, 1997; Crystal and Sambamoorthi, 1996).

This article uses a database of paid Medicaid claims to examine patterns of home-care service use and expenditures among PWAs in the New Jersey Medicaid program. We examined overall home-care use and patterns of use among participants and non-participants in the New Jersey Medicaid AIDS Community Care Alternatives Program (ACCAP), a 1915c AIDS-specific waiver instituted in 1987. We investigated whether there are sociodemographic or risk group differences in the use of home-care services in this population and whether those differences are smaller in the ACCAP population.

We derived our study population from a file match between the New Jersey Medicaid eligibility file and the State's AIDS Registry. The file match was conducted under a cooperative agreement between the New Jersey Department of Health and Senior Services (DOHSS),

which manages the AIDS Registry, and the State's Department of Human Services, Division of Medical Assistance and Health Services (DMAHS), which administers the Medicaid program. The match covered persons eligible for Medicaid by March 1996 and persons in the State's AIDS Registry through March 1996. Dates of AIDS diagnosis were determined from the Registry and claims histories were extracted from adjudicated claims files, covering the period from 1988 until death or March 1996 (the last date through which claims histories were considered complete and vital status information was available). This file match updates a previous 1992 match which the AIDS Research Group used to conduct an unpublished analysis similar to that undertaken for the present article (Crystal et al., 1997).

## HOME AND COMMUNITY-BASED WAIVERS

The public burden for AIDS care has grown over the life of the epidemic. In 1997, combined Medicaid, Medicare, and Ryan White CARE Act spending totaled \$5.8 billion (Graydon and Gordon, 1999). However, Medicaid has remained the largest public payer for AIDS-related medical care services, primarily because the epidemic has affected disproportionate numbers of low-income people and because even those people living with HIV/AIDS who are not low income to begin with generally spend-down their assets until they are eligible for Medicaid (Markson et al., 1994). Though HCFA changed its assumptions regarding its estimates of Medicaid expenditures on AIDS in 1994, making year-to-year comparisons more difficult, it is likely that Medicaid spending on AIDS care doubled between 1990 and 1997 to \$3.3 billion, more than twice the level of annual AIDS spending by

<sup>2</sup> There are 16 active approved home and community-based waiver programs for PWAs—California, Colorado, District of Columbia, Delaware, Florida, Hawaii, Illinois, Iowa, Missouri, New Jersey, New Mexico, North Carolina, Pennsylvania, South Carolina, Virginia, Washington (Tyler, 1999).

Medicare or by programs funded by the Ryan White CARE Act (Graydon and Gordon, 1999). Much of the spending increase has been driven by high inpatient care costs, particularly towards the end of life (Hellinger, Fleishman, and Hsia, 1994; Fleishman, Mor, and Laliberte, 1995). Estimates of the share of total AIDS medical costs attributable to inpatient care range from 63 percent to 89 percent, but have fallen over the course of the epidemic (Hellinger, 1993; Merzel et al., 1992).

To encourage States to treat AIDS patients in less costly non-institutional settings, the 1985 Omnibus Budget Reconciliation Act (OBRA) amended the original section 2176 of the 1981 OBRA, which established the 1915c program for the elderly and disabled, to include AIDS-specific waiver programs for home and community-based care. States can opt to provide waiver services to PWAs either through AIDS-specific programs or through programs designated for the disabled (Buchanan and Chakravorty, 1997). In addition, States must offer basic home-care services through their Medicaid programs to all enrollees in order to receive Federal matching funds (Ettner and Weissman, 1994). States began implementing 1915c waivers specifically for PWAs in 1987 (Miller, 1992).

The 1915c waiver legislation specifically lists seven services which may be provided in State programs: (1) case management, (2) homemaker services, (3) home health aide services, (4) personal care services, (5) adult day health, (6) habilitation, (7) respite care. HCFA may also grant approval for other services if they are needed by waiver participants to avoid being placed in a medical facility, such as transportation, in-home support services, meal services, special communication services, minor home modifications, and adult day care. States have the flexibility to

design each waiver program and select the mix of waiver services that best meets the needs of the population they wish to serve.

The New Jersey Department of Human Services, which was already operating 1915c programs for the elderly, developmentally disabled, and children and adults in need of nursing services, began operating ACCAP in 1987 (Conviser, Young, and Grant, 1992; Crystal et al., 1989). The first of its kind in the country, ACCAP is a statewide program available on a voluntary basis to persons with HIV disease who are deemed to have medical and social needs that would otherwise require care in a skilled nursing or intermediate-care long-term care facility (Crystal et al., 1997). Waiver participants also receive "State plan" home-care services which are available to all Medicaid enrollees and include skilled nursing, home health aides, and medical social services, provided through State-licensed home health agency providers (Crystal et al., 1997).

To encourage participation, the waiver program is available to individuals with income levels above the regular Medicaid income threshold, up to the income level at which they would become financially eligible if institutionalized (Crystal et al., 1997). As of February 1998, there were 1,000 approved, county-specific slots in ACCAP statewide, of which 82 percent (817) were filled. (New Jersey Department of Human Services, 1998). Most counties had significant numbers of unfilled slots, but in counties with high HIV prevalence rates, participation was high—86 percent capacity compared with 66 percent capacity in lower prevalence counties. For example, two high prevalence counties near New York City, Hudson and Union, were 97 percent and 89 percent full, respectively. The fact that some slots remained unfilled, in contrast to the situation with home and community-based waivers for some other tar-

get populations in the State, may reflect the impact of eligibility limitations; Federal guidelines for AIDS require that waiver programs serve clients who would otherwise require institutional care. However, recruitment and/or retention processes could be contributing to low enrollment rates as well.

A central component of ACCAP is mandatory case management, wherein case managers are required to maintain weekly contact with their clients and make monthly home visits. Case managers, typically registered nurses, are responsible for planning, coordinating, monitoring, and securing the services needed to maintain clients at home, but arranging and securing home-care services typically comprises a large part of their workload. In addition to case management, adult clients are eligible to receive five other waived services: (1) private duty nursing by a registered nurse or licensed practical nurse, (2) personal care assistance, (3) specialized medical day care for persons with HIV, (4) home-based narcotic and drug abuse treatment, and (5) home-based hospice service, which was implemented in 1992. ACCAP participation influences home-care use both because ACCAP participants have access to home-care services not available to non-ACCAP participants, and because the case management component of ACCAP facilitates access to home-care services, including State plan (non-waivered) services (Crystal et al., 1997).

## **EVALUATIONS OF AIDS-SPECIFIC WAIVERS**

To date, there is little published research on the type of participants in the AIDS waiver programs, their service use and expenditures, and the ability of the programs to reduce access barriers to home care among disadvantaged groups.

Several evaluations of home-care programs for elderly Medicare populations have found that home-care services are complements to, rather than substitutes for, institutional care. These programs have been, on balance, cost increasing, though this may be less true where they are carefully targeted at those elderly at greatest risk of nursing home placement (Anderson and Mitchell, 1997). In the AIDS case, since the AIDS home-care waiver programs were developed primarily to reduce inpatient care, as opposed to nursing home care, the potential for cost savings may be relatively greater than in the programs for the elderly (Anderson and Mitchell, 1997).

There is some published research on AIDS-specific home and community-based care waivers which suggests that they may be cost-saving and that participants and case managers appear to be satisfied with them. Merzel et al. (1992) found that the average inpatient costs for waiver participants in New Jersey's ACCAP program were nearly 30 percent less than those for all New Jersey AIDS patients during the period of 1987-1989. Anderson and Mitchell (1997) found that participants in Florida's Project AIDS Care, an AIDS-specific Medicaid waiver program in operation since 1990, had monthly Medicaid expenditures that were on average 22-27 percent lower than similar, non-waiver participants. Crystal, Sambamoorthi, and LoSasso (1998) also found that in bivariate comparisons, monthly inpatient expenditures for waiver participants followed from AIDS diagnosis to death were less than one-half those incurred by non-waiver participants, and overall monthly expenditures were 37 percent lower. Multivariate analyses, adjusting for patient characteristics and selection, indicated that waiver participants utilized substantially fewer inpatient services and more outpatient services per month than traditional Medicaid recipi-

ents, with overall similar total monthly cost of care for the two groups. The higher monthly cost of home care and other non-inpatient services utilized by waiver participants was offset by lower monthly inpatient costs. Controlling for demographic characteristics, waiver participants received more frequent physician/clinic visits and spent a higher proportion of enrollment time on antiviral therapy than was the case for non-waiver clients. Waiver program participation appeared to substantially reduce racial, sexual, risk group, and geographic inequalities in utilization of outpatient services, which were apparent among participants in the traditional Medicaid program.

In the only study to date that attempts to measure quality of care in 1915c AIDS-specific waiver programs, Cowart and Mitchell (1995) found general satisfaction with Project AIDS Care in Florida among participants. Satisfaction was also high among the program's case managers, who, despite long hours and high mortality rates in a very sick population of patients, had low turnover rates. The authors found that the major frustration to both case managers and participants was the strict eligibility requirements of the program.

Research on the sociodemographics of AIDS patients who use home-care services suggests that use is concentrated among white persons, males, and non-IDUs. Cowart, Mitchell, and Meyer (1994) reported that participants in Florida's Project AIDS Care included proportionately fewer black persons and Hispanics than non-participants or all Medicaid beneficiaries with AIDS in Florida. Instead, waiver participants were more likely to be white and male than non-participants. Ettner and Weissman (1994), who compared the use of home care services between IDUs and homosexual males in Boston, found that IDUs were significantly less likely to use

formal home-care services than homosexual males, and that they used more informal home-care.

Previous research by the Rutgers AIDS Research Group on the New Jersey ACCAP program using early 1990s data found that the program tended to mitigate racial, risk-group, and sex-related access barriers to home care (Crystal et al., 1997). Black persons, Hispanics, females, and IDUs were found to be less likely to use home-care services relative to comparison groups (white persons, males, and non-IDUs, respectively), but these differences generally were not apparent in the waiver program. Still, black persons, females, and IDUs were less likely to be enrolled in the waiver program relative to the comparison groups (Crystal, Sambamoorthi, and LoSasso, 1998).

This article seeks to extend this previous work using a more recent database. It aims to fill a substantial gap in what is known about the sociodemographic and risk groups that use AIDS home-care services, and to explore the extent to which waiver programs with their hallmark case-management components are able to increase the use of home and community-based services by those most at risk of using inpatient care. However, some limitations of the study should be noted. The study documents the experience of AIDS patients in one particular State and may not be representative of other State programs. The application of our conclusions to States other than New Jersey depends upon both the characteristics of their AIDS populations and the operational factors associated with Medicaid enrollment, including eligibility criteria and enrollment process. In addition, many States have opted to provide home and community-based services to people living with HIV/AIDS through other mechanisms. Some States, for example, include people

living with HIV/AIDS in their 1915c waiver programs for the elderly and persons with disabilities, rather than implementing AIDS-specific waivers. Also, after the enactment of the Balanced Budget Act in 1997, 19 States implemented Medicaid managed care plans that include home and community-based services (Conviser, Gamliel, and Honberg, 1998). Nevertheless, the fact that 16 States have AIDS-specific waivers, many of which are into their third renewal period, suggests a need for understanding the way in which such programs impact access to home and community-based services. As in all observational research, it is essential to remain alert to possibilities of unobserved selection effects. For example, outcome differences for those participating and not participating in the waiver program will represent a combination of program effects and selection effects. However, we explored this issue to the extent possible with sensitivity analyses as discussed later.

## **METHODS**

### **Study Population**

The study population used in these analyses reflects the population of PWAs participating in Medicaid in New Jersey, identified through a file match between the New Jersey Medicaid eligibility file and the State's AIDS Registry through March 1996, which was conducted under a cooperative agreement between the New Jersey DOHSS, and the State's DMAHS. The link between the AIDS Registry and the Medicaid file was accomplished using a matching algorithm utilizing identifying fields common to both files. These date elements included the name, birth date, sex, and social security number fields. To perform the database link, a methodology suitable for determining database intersec-

tions where only partial overlaps are expected was used. A detailed description of a similar match process has been reported by researchers in Maryland (Hidalgo, 1990), where it has been used successfully to report on trends in Medicaid enrollment for PWAs (Bartnyska, Schactman, and Hidalgo, 1995).

Medicaid claims histories were run on the population identified by the match in December 1996, and subsequently provided to the researchers, who cleaned and organized these utilization data and merged them with data elements from the AIDS Registry and other administrative files such as waiver program client files. The claims histories contained all processed claims for services provided up to December 1996. To allow for time lags between receiving services, billing, payment, and appearance of paid claims in the computerized database and because vital status information was available as of March 1996, services received through March 29, 1996 were included in the analyses. The claims files provided information on category of service, dates of service, and actual amounts paid by Medicaid for each of the services. Home-care claims in the Medicaid file also contained procedure codes, either Current Procedural Terminology (CPT) codes or HCFA Common Procedure Coding System (HCPCS) level 2 (National) or 3 (State level) codes. Identifying information was stripped in order to protect confidentiality and the individual records were linked by unique Medicaid numbers.

We used the following criteria to define our study population: diagnosis with AIDS by March 1996; age 18 or over at the time of diagnosis; presence on the Medicaid eligibility file by March 1996; Medicaid participation for at least 30 days during some part of the period from January 1988 through March 1996; and no participation

in Medicare<sup>3</sup> or managed care programs. We identified 3,916 patients who met these criteria for inclusion, of whom 606 (15.5 percent) participated in the waiver program and 3,310 (84.5 percent) did not.

## MEASURES

Expenditure data were based on the actual amount reimbursed by the New Jersey Medicaid program and are reported in 1996 dollars based on the national medical care Consumer Price Index. Since the observation period varied among subjects depending on the start date of Medicaid participation and survival time, we computed expenditures per month. Monthly expenditures were calculated by dividing the total cost per patient by the number of months of Medicaid participation.

The mix of home-care service utilization was examined across the following categories: home nursing, paraprofessional, and miscellaneous services. Type of home-care service was identified through the HCPCS procedure codes. Home nursing included skilled nursing and licensed practical nursing (LPN) services.<sup>4</sup> Paraprofessional services included personal care assistance and home health aide services.<sup>5</sup> Miscellaneous home-care services included psychotherapy, home drug treatment, medical day care, medical social services, and hospice.<sup>6</sup> Because everyone participating in ACCAP received case man-

agement, we excluded case management visits from expenditure and home-care use measures.

Demographic characteristics (sex, race, age at diagnosis), exposure category, date of AIDS diagnosis, vital status and date of death for decedents were derived from the State's AIDS Registry. Exposure category was based on drug use history as reported in the AIDS Registry, and patients were classified as IDUs and Non-IDUs. Mortality status was ascertained as of March 1996 and people were categorized as either dead, alive, or unknown. Alive ( $n = 2,713$ ) and unknown cases ( $n = 29$ ) were grouped as non-decedents. In our regressions, we included vital status as a covariate and compared utilization patterns of decedents with non-decedents.

Geographical areas of New Jersey vary widely in HIV/AIDS prevalence and, therefore, in the extent to which the health care system has been impacted by the demands of AIDS care. The highest-prevalence area of the State for HIV/AIDS is the five-county area nearest to New York City, comprising Essex, Hudson, Passaic, Bergen, and Union Counties. This is an area with a high prevalence of poverty and HIV. It includes such inner-city localities as Newark, Jersey City, and Paterson, and represents an area in which the health care system has had to respond to a substantial and growing volume of HIV/AIDS care needs. In our analyses, we included region as a covariate and contrasted utilization patterns in this high-prevalence region to those in the remainder of the State.

Since waiver participants have access to various types of in-home-care services that are not available to traditional Medicaid enrollees, we separately examined home-care use for non-waiver and waiver program enrollees. We derived an indicator

<sup>3</sup> We excluded those PWAs who were dually eligible for Medicaid and Medicare since we would be unable to examine the full range of their service use in the Medicaid claims.

<sup>4</sup> Procedure codes for skilled nursing and LPN services were Z1710, Z1715, Z1720, Z1725, Z1730, Z1735, Z1740, Z1745, HH550, HH551, and HH552.

<sup>5</sup> Paraprofessional service codes were Z1600 through Z1617, Z1820 through Z1829, Z1860, Z1864, HH570 through HH572, HH560, HH561, and W9002. Codes 90050 or 92507 identified personal care assistant services.

<sup>6</sup> Miscellaneous home-care services were identified by procedure codes Z1830, Z1810, Z1832 through Z1834, HH270 through HH441, HH580 through HH600.

variable for participation in the waiver program by matching the claims file against the ACCAP client profile file provided to us as of May 1996. If the client appeared in both files, we classified the patient as a waiver participant. A separate file match of the AIDS cases in AIDS Registry and cumulative ACCAP cases revealed that nearly 90 percent of the waiver participants were matched. The reasons for non-match included death of the participant before the eligibility process was completed, moving out of State, and other reasons.

## STATISTICAL TECHNIQUES

We used a combination of bivariate statistical methods and multivariate models in addressing our research questions. We tested for subgroup differences in the proportion of PWAs who utilized home-care services using chi-square statistics. We also examined average monthly expenditures for home-care services during the period of followup. The statistical significance of bivariate subgroup differences in average monthly expenditures of home-care services was evaluated with *t*-tests.

We employed separate logistic regressions to estimate the effect of beneficiary characteristics on the odds of using any home-care service, home nursing and paraprofessional services. Parameter estimates from logistic regressions were transformed into odds ratios associated with each independent variable, which represent the relative risk ratios for a one-unit change in the dependent variable in question. Odds ratios that exceed one indicate an increased likelihood of using home-care services relative to the comparison group, while odds ratios less than one indicate a decreased probability of using home-care services.

Ordinary least square (OLS) regressions were used to test subgroup differences in monthly home-care expenditures

among users. Total home care, professional, and paraprofessional expenditures were assessed with separate OLS regressions, for non-waiver and waiver program enrollees. For these analyses, monthly expenditures were transformed to a logarithmic scale to reduce skewness. Effect estimates for continuous independent variables on the log of monthly expenditures can be interpreted as percentage change for each unit of change in the independent variable. The effect of dummy variables in terms of percentage of expenditures can be estimated by exponentiating the regression coefficients of dummy variables and subtracting 1 (i.e., percent change= $e^{\beta}-1$ ) (Halvorsen and Palmquist, 1980). The differences in parameter estimates for sex, race, risk group, and geographic location effects from the two sets of regression equations were tested for statistical significance using the Chow test of inequality.

In social programs such as ACCAP which are voluntary and have eligibility requirements, the assignment of individuals to the two groups is by self-selection rather than by random assignment. Under self-selection, more-advantaged individuals might be more likely to join the program. To investigate the possibility that unobserved selection factors might bias estimates of differences in outcomes between traditional Medicaid beneficiaries and ACCAP participants, we conducted a sensitivity analysis using a two-stage sample selection procedure (Maddala, 1992). In the first stage, we conducted a probit analysis of the probability of participation in the waiver program, controlling for sex, race, age, year of diagnosis, months from diagnosis to Medicaid participation and geographic location. Geographic location, in the selection equation, included dummies for individual counties near New York City. The estimated probabilities from the selection equation were then used to calculate

predicted rates of waiver participation for each sample subject, correcting for the non-random selection of subjects into the waiver program. In the second stage, we predicted outcomes based on the waiver participation rate derived in the first stage (inverse Mills ratio), along with the other control variables. Results from the estimation of the probit model of program selection indicated that females, racial minorities, IDUs, and those who lived in high prevalence counties were all less likely to participate in the waiver program (data not shown). However, the selectivity term in the outcome regressions was insignificant and did not justify the selectivity corrected model. Additionally, the results from the outcomes regressions controlling for selection were similar to the findings from the models without selectivity correction. Therefore, in this article, we report only the models without selectivity correction.

## FINDINGS

### Characteristics of Study Population

Demographics of the study population are shown in Table 1. The population was 62 percent male and 38 percent female; 60 percent black, 21 percent white, and 18 percent Hispanic; and 62 percent IDU. Sixty-seven percent of the population lived in the high-HIV prevalence area of the State, near New York City. Seventy percent of the sample was alive as of March 1996. About 15 percent of the population was enrolled in the waiver program. The study population, like the New Jersey AIDS population, included more females, black persons, and IDUs than is characteristic of the national AIDS population. However, the national AIDS population is moving in the direction of greater representation of these demographic groups (Schore et al., 1997).

There are differences in the demographic makeup of the waiver and non-waiver populations relative to the statewide AIDS population. The waiver population is fairly similar to the statewide AIDS population on the basis of sex, but differs in that it has a lower share of black persons than the statewide AIDS population and a correspondingly higher share of white persons, a higher share of IDUs relative to non-IDUs, a lower share of people living in counties near New York City, and a lower share of decedents.<sup>7</sup> In contrast, the non-waiver Medicaid population with AIDS included a higher proportion of females, black persons, and people living near New York City than the statewide population of PWAs. However, the non-waiver Medicaid population, like the waiver population, had a higher share of IDUs than the statewide population. The demographics of the study population were largely similar to those of the earlier unpublished research by the AIDS Research Group (Crystal et al., 1997) which used data from a 1992 AIDS Registry-Medicaid eligibility. The demographic similarities were observed across the study population and within the waiver and non-waiver groups.

Table 2 provides bivariate comparisons of the proportion with any home-care use and their average monthly expenditures by waiver status. Overall, 35 percent of Medicaid recipients with AIDS in our sample used home-care services at some point during their illness. Use of any home-care services was substantially higher in the waiver population than in the non-waiver population—83 percent of waiver program participants in our sample used any home-care services (other than case management) compared with 25 percent of the

<sup>7</sup>The difference between the vital status of the study population and the statewide population derives from the fact that the statewide population statistics are cumulative AIDS cases.

**Table 1**  
**Non-Waiver and Waiver Participants of Study Population Compared with New Jersey and National Registry Data**

Characteristic	New Jersey Medicaid <sup>1</sup>			All PWAs	
	All (n=3,916)	Non-Waiver (n= 3,310)	Waiver (n=606)	New Jersey Registry <sup>2</sup> (n= 29,639)	National Registry <sup>3</sup> (n= 548,102)
	Percent				
<b>Sex*</b>					
Male	61.6	60.0	70.3	73.5	85.0
Female	38.4	40.0	29.7	26.5	15.0
<b>Race*</b>					
White	21.3	18.0	39.9	29.5	48.9
Black	60.1	63.4	42.2	54.4	36.0
Hispanic	18.2	18.4	17.3	16.1	15.1
<b>Risk Group*</b>					
IDUs	61.6	63.5	51.2	40.3	32.0
Non-IDUs	27.9	25.8	39.1	59.7	68.0
<b>County of Residence*</b>					
Near New York City	66.9	70.2	49.3	58.8	—
Elsewhere	33.1	29.8	50.7	41.2	—
<b>Vital Status as of March 1996*</b>					
Decedents	30.0	26.0	51.8	63.9	62.6
Non-decedents	70.0	74.0	48.2	36.1	37.4
<b>Age at Diagnosis</b>					
Under 50 Years	94.0	94.1	93.2	90.7	89.8
50 Years or Over	6.0	5.9	6.8	9.3	10.2
<b>Year of Diagnosis*</b>					
Before 1993	25.2	24.3	30.4	—	—
1993-1996	74.8	75.7	69.6		
Months of Followup**	21.0	21.2	19.7	—	—

<sup>1</sup> Criteria for inclusion in our study population included: diagnosis with AIDS by March 1996; age 18 or over at the time of diagnosis; presence on the Medicaid eligibility file by March 1996; Medicaid participation for at least 30 days during some part of the period from January 1988 through March 1996; and no participation in Medicare or managed care programs.

<sup>2</sup> Cumulative AIDS cases through March 1996.

<sup>3</sup> Cumulative AIDS cases through June 1996.

\*Chi-square test;  $p \leq 0.05$ .

\*\* t-test;  $p \leq 0.05$ .

NOTES: PWAs is persons with AIDS. IDUs is injection drug users. AIDS is acquired immunodeficiency syndrome.

SOURCES: Authors' computations from New Jersey Medicaid claims data, 1998; New Jersey State Department of Health, 1996; and Centers for Disease Control and Prevention, 1996.

non-waiver population. Sixty-nine percent of the waiver participants used home nursing services and 62 percent used paraprofessional home-care services. In contrast, only 20 percent of non-waiver participants used home nursing services and 16 percent used paraprofessional services. Also displayed in the table is mean monthly expenditures among all beneficiaries and among users of home-care services by waiver status. For each type of service, in

general, we found significant differences in the costs of home-care services between waiver and non-waiver participants.

### UTILIZATION: ALL HOME CARE SERVICES

We stratified our sample into waiver and non-waiver groups and estimated logistic regressions on use of home-care services (Table 3). We found substantial race and

**Table 2**  
**Expenditures and Use of Home-Care, by Type of Service and Waiver Participation<sup>1</sup>**

Characteristic	Non-Waiver Participants	Waiver Participants	All
<b>Mean Expenditures*</b>			
Total	**\$93.0	\$577.1	\$167.9
Home Nursing	**35.1	157.4	54.1
Paraprofessional	**50.2	383.4	101.7
<b>Mean Expenditures Among Users*</b>			
Total	**369.1	693.9	491.4
Home Nursing	168.7	227.6	191.0
Paraprofessional	**310.1	619.6	437.6
<b>Use***</b>			
		Percent	
Home Nursing	**20.2	69.1	28.3
Paraprofessional	**16.1	61.9	23.2
Any Home Care	**25.2	83.2	35.2

<sup>1</sup> Criteria for inclusion in our study population included: diagnosis with AIDS by March 1996; age 18 or over at the time of diagnosis; presence on the Medicaid eligibility file by March 1996; Medicaid participation for at least 30 days during some part of the period from January 1988 through March 1996; and no participation in Medicare or managed care programs.

\*t-test.

\*\*  $p \leq 0.05$ .

\*\*\*Chi-square test.

NOTE: AIDS is acquired immunodeficiency syndrome.

SOURCE: Authors' computations from New Jersey Medicaid claims data, 1998.

risk group differences among non-waiver participants which were not apparent in the waiver group. For example, black persons were significantly less likely than white persons to use home-care services in the non-waiver group, but the differences were not significant in the waiver population. Similarly, IDUs were significantly less likely than non-IDUs to use home-care services among non-waiver participants, but there were no significant differences between the two groups within the waiver program.

Females were more likely to use home-care services than males in both waiver and non-waiver groups. There were also differences in the likelihood of using services among decedents and non-decedents. Decedents were far more likely to have used home-care services in the non-waiver and waiver groups, but the difference between decedents and non-decedents was somewhat smaller in the waiver group.

## UTILIZATION: HOME CARE SERVICES SUBGROUPS

In order to provide overall comparisons of the types of service utilized, home-care services were grouped into professional (home nursing), paraprofessional, and specialty services. Professional or home nursing included registered nursing (RN) and LPN services provided as a waived service and as a State plan service. Among waived services, we defined personal care assistants as paraprofessional services and among State plan services we defined home health aide services as paraprofessionals. Home nursing and paraprofessional services represent the most widely used services and most of the expenditures. Specialty services, which are not shown in this article, include the waived services of home drug treatment, medical day care, and hospice, and the traditional Medicaid home medical social services. Since home

**Table 3**  
**Logistic Regression on Home-Care Use, by Service Type and Waiver Participation<sup>1</sup> Odds Ratios**

Characteristic	Non-Waiver Participants			Waiver Participants		
	Any	Home Nursing	Para-professional	Any	Home Nursing	Para-professional
<b>Sex</b>						
Female	*1.73	*1.83	*1.63	*1.94	*1.58	*3.60
<b>Race/Ethnicity</b>						
Black	*0.80	*0.76	0.91	0.86	1.15	0.98
Hispanic	0.81	0.78	0.97	1.17	1.16	1.55
<b>Risk Group</b>						
IDU	*0.66	*0.71	*0.60	1.48	*1.53	1.07
<b>Region</b>						
Near New York City	0.97	*0.82	*1.33	1.10	*0.53	*1.64
<b>Age at Diagnosis</b>						
50 Years or Over	0.96	1.04	0.79	2.75	1.56	1.79
<b>Vital Status as of March 1996</b>						
Decedents	*3.36	*3.85	*3.46	*1.94	*1.87	*2.06
<b>Year of Diagnosis</b>						
Before 1993	0.99	1.05	0.97	0.99	0.79	0.83
Months of Followup	*1.02	*1.02	*1.01	1.01	*1.02	0.99

<sup>1</sup> Criteria for inclusion in our study population included: diagnosis with AIDS by March 1996; age 18 or over at the time of diagnosis; presence on the Medicaid eligibility file by March 1996; Medicaid participation for at least 30 days during some part of the period from January 1988 through March 1996; and no participation in Medicare or managed care programs.

\*  $p \leq 0.05$ .

NOTES: IDU is injection drug user. AIDS is acquired immunodeficiency syndrome.

SOURCE: Authors' computations from New Jersey Medicaid claims data, 1998.

nursing services and paraprofessional services make up the majority of expenditures for waiver enrollees (93 percent) and for non-waiver enrollees (91 percent), we present results in terms of those two categories.

There were consistent patterns of utilization across both waiver and non-waiver groups in home nursing and paraprofessional services. Females and decedents were more likely to use both skilled home nursing and paraprofessional services. These results also indicated a significant regional difference in the service mix of home-care services, regardless of waiver status. While residents near New York City were more likely to use paraprofessional services (compared with their counterparts in other regions of the State), residents of other regions of New Jersey were much more likely to use skilled home nursing services.

We found, however, important differences between the non-waiver and waiver groups in home nursing service use. Black persons were significantly less likely than white persons to use home nursing services in the non-waiver group, but the differences were not significant in the waiver population. Whereas, IDU status was associated with a reduced likelihood of using home nursing services in the non-waiver group (compared with non-IDUs), it was associated with an increased likelihood in the waiver group.

### **HOME CARE EXPENDITURES AMONG USERS**

The results from multivariate analyses of average monthly home-care expenditures among users are reported in Table 4.

**Table 4**  
**OLS Regression on Log Monthly Home-Care Expenditures (1996 Dollars), by Service Type and Waiver Participation<sup>1</sup> Among Users**

Characteristic	Non-Waiver Participants			Waiver Participants		
	Total	Nursing Home	Para-professional	Total	Nursing Home	Para-professional
<b>Sex</b>						
Female	0.02	-0.09	-0.004	*0.39	0.21	0.26
<b>Race/Ethnicity</b>						
Black	0.29	0.24	*0.48	0.23	0.01	*0.57
Hispanic	0.14	0.13	0.17	0.30	0.02	0.18
<b>Risk Group</b>						
IDU	*-0.41	*-0.29	*-0.49	*-0.54	*-0.48	*-0.48
<b>Region</b>						
Near New York City	*0.001	*-0.32	0.30	0.16	*-0.53	*0.73
<b>Age at Diagnosis</b>						
50 or Over	-0.10	-0.05	0.29	0.12	0.05	0.18
<b>Vital Status as of March 1996</b>						
Decedents	*0.32	*0.41	-0.05	*0.72	*0.47	*0.39
<b>Year of Diagnosis</b>						
Before 1993	*-0.69	*-0.77	-0.61	*-0.62	*-0.54	*-0.46
<b>R<sup>2</sup></b>	0.07	0.11	0.07	0.10	0.12	0.13

<sup>1</sup> Criteria for inclusion in study population included: diagnosis with AIDS by March 1996; age 18 or over at the time of diagnosis; presence on the Medicaid eligibility file by March 1996; Medicaid participation for at least 30 days during some part of the period from January 1988 through March 1996; and no participation in Medicare or managed care programs. Reference categories: male, white, non-IDU, not near New York City, under 50, alive, diagnosed 1993 or later.

\*  $p \leq 0.05$ .

NOTES: OLS is ordinary least squares. IDU is injection drug user. AIDS is acquired immunodeficiency syndrome.

SOURCE: Authors' computations from New Jersey Medicaid claims data, 1998.

Separate regressions were run for home-care, home nursing, and paraprofessional services, to examine differences in monthly expenditures by type of service across waiver and non-waiver populations. Among users of each type of service, expenditures did not vary significantly by sex. The results show that while females were more likely to use both home nursing and paraprofessional services, after initiating the use of services their expenditures were similar to those of other PWAs, regardless of waiver status. Black race had a positive and significant effect on expenditures for paraprofessional services in both the waiver and non-waiver groups, but insignificant effects on home nursing expenditures. IDU status had a negative and significant

effect on home nursing and paraprofessional service expenditures among users both in non-waiver and waiver groups. This finding suggests that while waiver participation may increase the likelihood that IDUs receive any home-care services, IDUs have lower expenditures on services, even in the waiver program.

In this analysis, too, there were marked differences in service mix by region of the State. Residence near New York City had a positive and significant impact on the use of paraprofessional services in the waiver population (though not in the non-waiver population), and residence in this area had a negative and significant impact on the expenditures for home nursing services in both the waiver and non-waiver populations.

## DISCUSSION

This article used a database of Medicaid claims uniquely suited to examine patterns of home-care service use and expenditures among PWAs in the New Jersey Medicaid program, both participants and non-participants in the State's ACCAP, a 1915c AIDS-specific waiver instituted in 1987. This research extended earlier unpublished research by the AIDS Research Group (Crystal et al., 1997) by using a more recent dataset. The sample size for the more recent database is three times that of the earlier sample, but the demographic patterns are remarkably similar.

The major difference between the two cohorts was in waiver participation rates—33 percent in the earlier sample compared with 15 percent in the more recent sample. This may reflect improving functional status within the overall AIDS population as a result of superior HIV therapies. However, unless treatments improve enough to achieve permanent remission of HIV disease, PWAs are likely to eventually become impaired enough to need home-care services. Therefore, it continues to be important to develop mechanisms to assure equitable access to these services. These needs may be episodic rather than long term and stable, suggesting the importance of flexibility in case management and service authorization; longitudinal studies of functional impairment in HIV disease suggest that month-to-month variability in impairment is substantial, with worsening and improvement both common occurrences (Crystal and Sambamoorthi, 1996). Newer treatments may reduce the proportion of AIDS patients who have severe functional limitations; however, it is likely that individuals on these complex regimens can benefit from nursing-oriented case management services such as those offered through waiver programs. This

may suggest the need to develop mechanisms outside the home and community-based care waiver structure to deliver such case management services to Medicaid patients, perhaps through targeted case management mechanisms.

Another important variation between the two analyses occurred in the area of sex differences in home-care service use. In contrast to previous research suggesting that females were less likely than males to use home-care services, the present analysis found that females consistently showed a greater propensity to initiate use of home-care services across both waiver and non-waiver groups, although no sexual differences were observed among users of services. This latter finding is consistent with some evidence that females with AIDS may have a higher degree of functional impairment and fewer informal caregivers (Crystal and Sambamoorthi, 1996). Consequently, females may be more likely to turn to formal sources to meet those needs while males rely mainly on female relatives as caregivers, usually a mother or spouse. The study results suggest that the waiver program may have become increasingly effective at identifying and addressing the particular needs of females with AIDS. It is also possible that females, who are more likely than males to have been participants in the traditional Medicaid program prior to the onset of AIDS, may be less likely to enter the waiver program unless they have very substantial home-care needs, producing a pattern of more frequent use of such services by females within the waiver program.

Consistent with previous findings, a racial gap was found in the probability of any home-care use among non-waiver participants, but no such gap was found among waiver participants. In multivariate logistic analysis of home nursing use, the odds of using home care among black per-

sons were significantly lower than for white persons within the non-waiver sample, but these differences were insignificant in the waiver sample. Thus, waiver status appears to remove access barriers to home-care service use among its minority enrollees. It should be noted, however, that black persons are underrepresented in the waiver program.

Waiver participation appears to eliminate the risk group differences in the probability of receiving home-care services, though IDUs were less likely than non-IDUs to participate in ACCAP. However, we also found that IDU status was negatively and significantly related to expenditures, across both service categories examined in this study. These differences were apparent even within ACCAP. These results are particularly troublesome because IDUs represent a large and growing segment of the HIV population. Additional efforts to identify and address the distinctive health care and social services needs of the IDU population may be warranted.

We found that home-care service mix varies substantially by geographic region in New Jersey, which is again consistent with our earlier research. Controlling for race, risk group and other demographic factors, our findings show that home-care service use among residents of counties near New York City was concentrated in paraprofessional services. In contrast, residents of other regions of New Jersey were far more likely to use skilled nursing services. Further research is needed to determine the cause of such a consistent finding.

In summary, the New Jersey ACCAP program appears to reduce racial and risk group differences in the likelihood of using home-care services among its participants. However, the program's successes are confined to its enrollees, among whom some subgroups of the AIDS population are underrepresented. In addition, IDUs

appear to experience barriers to home-care services even within the waiver program, since IDU status has a negative and significant effect on monthly home-care expenditures. Care of this population may be among the most challenging issues faced by States that are attempting to shift AIDS care from inpatient to home and community-based care settings. As the epidemic matures, there will be a continuing need to build on and adapt these programs to address the evolving nature of the HIV/AIDS population and the changing face of HIV clinical care.

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Reprint Requests: Usha Sambamoorthi, Ph.D., Institute for Health, Health Care Policy and Aging Research, Rutgers University, 30 College Avenue, New Brunswick, NJ 08901-1293. E-mail: sambamoo@rci.rutgers.edu