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Costs and Financing of Medicare Enrollees Living with HIV/AIDS in California

by June Eichner and James G. Kahn

Because Medicare does not cover a large part of the health care that its enrollees living with HIV/AIDS require, they need other coverage to supplement it. Medicaid is a major source of that supplemental coverage. In California, Medicare enrollees with HIV/AIDS who were also enrolled in Medi-Cal (California's Medicaid program) had total payments from both programs of \$177 million, or an average of \$28,956 per person in the fee-for-service-system in 1998. Of that total, Medicare paid for 38 percent, mainly for inpatient hospital and ambulatory care, while Medi-Cal paid 62 percent, mainly for prescription drugs. For these dual enrollees, many of Medicare's benefit gaps — including a large share of prescription drugs, nursing facility services, and home care — are being filled by Medi-Cal.

This analysis indicates that the incremental cost to the federal government of filling gaps in the Medicare benefits package would be considerably less than the full cost of the additional benefits. Through Medicaid and other programs, the federal government is already paying a substantial part of public program expenditures for dual enrollees with HIV/AIDS. Other issues to consider are how the dual Medicare-Medicaid funding streams affect the programs' cost efficiency, and from the perspective of Medicare enrollees and providers, how well the dual programs coordinate to meet the needs of people with HIV/AIDS and other chronic conditions.

Introduction

Background

Researchers estimate that one out of five adults who are receiving regular care for HIV are enrolled in Medicare (Bozzette et al., 1998). Those under age 65 become eligible for Medicare 24 months after becoming entitled to Social Security disability insurance (SSDI) benefits. To qualify for SSDI benefits, a person must meet a strict test of work disability — the inability to engage in substantial gainful activity because of a

physical or mental impairment that is expected to last at least one year or result in death.¹ In addition, the person must have paid Social Security taxes for a minimum number of years.

Of those with HIV/AIDS on Medicare, most (70 percent) are "dual enrollees" in that they are also enrolled in Medicaid (Goldman, 2001). California's Medicaid program, Medi-Cal, is available to aged, blind, and disabled persons who are low-income and have limited financial resources, as well as to needy families with children.² Most dual enrollees with HIV/AIDS qualify for Medi-Cal through Supplemental Security Income

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(SSI), which is available to low income, aged, blind or disabled individuals with limited income and assets. In California and most other states, SSI eligibility automatically entitles a beneficiary to Medicaid. Those with high medical expenses, but incomes too high to qualify for SSI, may qualify for Medi-Cal through its "medically needy" category.

Improvements in treatment are transforming HIV/AIDS from a short-duration fatal disease into a long-term chronic condition. Medical advances, including prescription drugs, have shifted care for HIV and other chronic diseases out of the hospital. As use of effective but very costly antiviral medications became commonplace by mid-1997, expenditures increased dramatically for prescription drugs but declined for inpatient and other services (Bozzette et al., 2001). Largely as a result of such antiretroviral therapies, more of those who are disabled with HIV/AIDS are living long enough to qualify for Medicare, and they are living longer than before. These enrollees are expected to be on Medicare for many years and to have substantial health care needs.

Table 1: Primary Source of Health Insurance for People with HIV/AIDS and a Regular Source of Care, 1996*

and a Regular Source of Care, 1996"		
Health Insurance	Percent	
Private insurance	32%	
Medicaid (without Medicare)	29%	
Medicare	19%	
— with Medicaid (13%)		
— without Medicaid (6%)		
Uninsured	20%	
* National data Source: Bozzette et al., 1998 and Goldm	an, 2001.	

People with HIV/AIDS receive their health coverage from a variety of sources. National data show that 19 percent of people with HIV/AIDS receiving medical care during the first two months of 1996 had Medicare, two-thirds of whom also had Medicaid (Table 1). In addition, 29 percent had Medicaid, but not Medicare; 32 percent had private insurance; while

20 percent were uninsured. Though most Medicare enrollees with HIV/AIDS have Medicaid, many Medicaid enrollees with HIV/AIDS who are under age 65 are ineligible for Medicare because: 1) they have not met the definition of disability for SSDI beneficiaries; 2) they do not have a sufficient work history to qualify for SSDI and therefore Medicare; or 3) they are waiting the 24 months for their Medicare to begin.

For enrollees with multiple coverage sources, which source pays for a particular health care claim depends on their type of coverage and the benefits covered. Medicare usually serves as the primary payer for dual enrollees, with Medicaid as the secondary payer. (The insurer that pays first on a claim is called the "primary payer;" the insurer that pays second on a claim is called the "secondary payer.") For the disabled population under age 65 with Medicare and private insurance, private insurance is the primary payer if the insurance was obtained through an employer with 100 or more employees, and Medicare is the secondary payer.³ Nonetheless, even those with Medicare and/or private insurance contribute to the cost of their care, as they pay for premiums, deductibles, coinsurance, and services that their health coverage does not cover.

In 2000, federal spending for health care services for people with HIV/AIDS was estimated to be \$6.2 billion. The federal share of Medicaid accounts for the largest share of federal spending on health care for people with HIV/AIDS (36 percent), followed by Medicare (28 percent), the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (26 percent), and other payers, including the Department of Veterans Affairs and other federal agencies (Table 2). Federal spending for HIV/AIDS increased substantially from 1995 to 2000. Over this five-year period, Medicare expenditures for people with HIV/AIDS grew by 70 percent, while the federal share of Medicaid increased 57 percent (Foster and Niederhausen, 2000). Medicare and Medicaid expenditures for HIV/AIDS care are expected to continue to rise, with Medicare costs growing primarily due to longer life expectancy of enrollees with HIV/AIDS, and Medicaid costs increasing, in part, because of a projected rise in prices of prescription drugs used in treatment.

Purpose and design of this analysis

Policymakers seeking to control costs and improve access to and quality of HIV/AIDS care are hampered by lack of data on health care costs and services used by the HIV/AIDS population. Though a number of studies have estimated aggregate-level national Medicare expenditures for people living with HIV/AIDS, few have analyzed the expenditures of the multiple payers that comprise an individual's system of care. This analysis is one of the first to attempt this.

Using Medicaid claims data from California's Medi-Cal HIV/AIDS database, this analysis describes dual enrollees living with HIV/AIDS in California, their financing sources, and their health care costs and financing sources. People living with HIV/AIDS have been of particular interest to policymakers because this population requires intensive health care, is relatively young, has high prescription drug costs, and is often unable to work. The experience of HIV/AIDS may also provide policymakers with insights into issues faced by other populations who have a chronic condition or are dually enrolled, as these Medicare enrollees face similar struggles finding and coordinating health coverage to pay for their health care needs. The issues of people living with HIV/AIDS are also relevant to the population that is over age 65, since many have multiple chronic diseases, high prescription drug costs, and limited income.

The state of California was chosen for this analysis because its HIV/AIDS population represents a signif-

Table 2: Sources of Federal Payments for Health Care Services for People with HIV/AIDS. FY 2000*

Payer	Percent
Medicaid	36%
Medicare	28%
Ryan White CARE Act	26%
Dept. of Veterans Affairs	7%
Other federal programs	4%
. 0	

Note: Does not total 100% due to rounding.

* National data

Source: Kaiser Family Foundation, 2000.

icant share (14 percent) of the nation's AIDS population⁴ and because of its available data. The analysis focuses on dual enrollees because they represent a large share of the Medicare HIV/AIDS population. They are of special interest to policymakers because they account for a disproportionate share of Medicare and Medicaid spending. Nationally, dual enrollees were only 17 percent of Medicare enrollees in 1997, but they accounted for 28 percent of Medicare spending. Dual enrollees were only 19 percent of Medicaid enrollees, but they accounted for 35 percent of Medicaid spending (Clark and Hulbert, 1998).

Along with information on Medicare expenditures for dual enrollees with HIV/AIDS in California, this analysis provides information on how much California's Medi-Cal program pays for services not covered by Medicare, what services Medi-Cal is paying for, and how costs are shared by Medicare and Medi-Cal. It also contrasts dual enrollee characteristics and health care expenditures with those who are enrolled in Medi-Cal but not Medicare (hereafter called Medi-Cal-only enrollees), providing a comparison of the enrollee groups' demographics and enrollment characteristics and serving as a baseline for comparing Medicare expenditures. In addition, it breaks out federal and state spending to help policymakers understand the implications of expanding Medicare's benefit package, thus, shifting resources between Medicare and Medicaid, and between federal and state budgets.

Data and methods used

This analysis was done using Medi-Cal claims data from California's Department of Health Services. The study assessed the characteristics of dual enrollees with evidence of HIV infection, the amount payers spent on medical services for this population, and how costs varied by disease stage (HIV vs. AIDS, based on diagnostic and/or drug codes from 1996-1998). The demographic and cost analyses in this paper are based on 1998 data. The study population is limited to those in fee-for-service Medi-Cal. (Though there is no documentation of the number of California's Medicare enrollees with HIV/AIDS enrolled in an HMO, sources familiar with this population believe that only 3 percent to 15 percent

choose to join.⁶) Information on Medicare spending is available only for those enrolled in both Medicare and Medi-Cal (dual enrollees). Medicare enrollees were identified as those who had at least one payment made by Medicare during the year.

Findings on California dual enrollees and Medi-Cal-only enrollees

The Medi-Cal HIV data file provided valuable information on the characteristics and costs of dual enrollees and Medi-Cal-only enrollees with HIV/AIDS. During 1998, the data file included 24,688 persons and 2.7 million paid claims (an average of 109 claims per person). Of the persons in the data file, 7,020 (28 percent) were classified as dual enrollees; 17,668 (72 percent) had Medi-Cal but not Medicare (Figure 1).

Characteristics of dual enrollees and Medi-Cal-only enrollees

Dual enrollees and Medi-Cal-only enrollees with HIV/AIDS differed by age, race, sex, eligibility

- Table 3: Sex by Enrollment Status -

Sex	Dual Enrollees	Medi-Cal-only
Male	86%	63%
Female	14%	37%

Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.

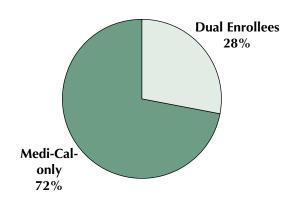
Table 4: Race and Ethnicity by Enrollment Status

Race and Ethnicity	Dual Enrollees	Medi-Cal- only
White	70%	45%
African American	22%	32%
Hispanic	7%	17%
Other	1%	7%

Note: Does not total 100% due to rounding. One-fifth of claims had missing data on race and ethnicity.

Figure 1

Enrollment Status of Medi-Cal Enrollees with HIV/AIDS



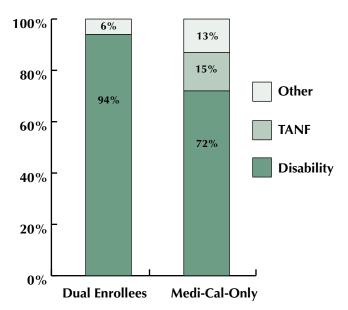
Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.

status, and disease stage. As shown in Tables 3 and 4, dual enrollees were more likely than Medi-Cal-only enrollees to be male (86 percent to 63 percent, respectively) and white (70 percent to 45 percent, respectively). In fact, one-half of dual enrollees were white males, compared to only 26 percent of Medi-Cal-only enrollees. Of those dually enrolled, only 22 percent were African American and only 7 percent were Hispanic.

With a mean age of 44 years, dual enrollees were older than Medi-Cal-only enrollees, who were 37 years on average. Almost 8 percent of dual enrollees were over age 65, compared to less than 1 percent of Medi-Cal-only enrollees. In contrast, 8 percent of the Medi-Cal-only enrollees were under age 18, though almost none of the dual enrollee population was under age 18.

Dual enrollees also were more likely than Medi-Calonly enrollees to be eligible for Medi-Cal due to disability (94 percent to 72 percent, respectively). Fifteen percent of Medi-Cal-only enrollees qualified for Medi-Cal by meeting its definition of a low-income family member (in California, eligibility requirements for CalWORKs, California's Temporary Assistance for Needy Families (TANF) program⁷ are equivalent to Medi-Cal's); none of those dually enrolled qualified for Medi-Cal this way (Figure 2).

Figure 2 Medi-Cal Recipient Category by Eligibility Status



Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.

Dual enrollees were more likely to have AIDS (90 percent) than were Medi-Cal-only enrollees (84 percent). This is consistent with the fact that persons receiving Social Security disability benefits must wait 24 months from the time they are entitled to SSDI benefits until they are eligible for Medicare. Those awaiting Medicare enrollment are probably those who are newly and less severely disabled than those already on Medicare. Some of them may progress to AIDS over the 24-month waiting period; others will progress to AIDS after becoming dually enrolled. Also, because Medi-Cal-only enrollees are more likely than dual enrollees to qualify for Medi-Cal through a low-income family program, they are less likely to have AIDS and may be ineligible for Medicare because they do not meet SSA's disability standards to qualify for Medicare.

Costs to Medicare and Medi-Cal for program enrollees

As the primary payer for Medicare-covered services for dual enrollees, Medicare pays for those services included in the Medicare benefit package. As the secondary payer, Medi-Cal pays for those services

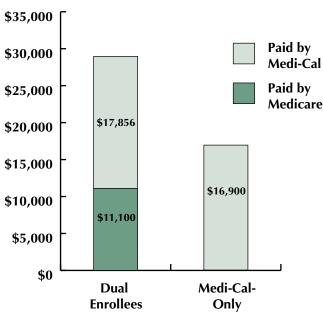
covered by Medi-Cal but not Medicare, and for Medicare premiums, coinsurance, and deductibles. Payments not included in the analysis because they are not in the data file are Medi-Cal payments for Medicare premiums, out-of-pocket payments by enrollees for those services not covered by Medicare or Medi-Cal, and payments by other payers.

Medicare and Medi-Cal expenditures for dual enrollees were significantly more than Medi-Cal expenditures for Medi-Cal-only enrollees. In 1998, dual enrollees averaged \$28,956 in annual Medicare-Medi-Cal payments⁸ compared to \$16,900 for Medi-Cal-only enrollees. Medicare paid 38 percent (\$11,100) of the expenditures for those dually enrolled, while Medi-Cal paid 62 percent of their expenditures (\$17,856) (Figure 3).

Medicare and Medi-Cal payments also were greater for dual enrollees when viewed by disease stage. Dual enrollees with AIDS had higher expenditures than Medi-Cal-only enrollees with AIDS (\$29,941 compared to \$17,600). Similarly, dual enrollees with HIV (non-AIDS) had higher expenditures than Medi-Calonly enrollees with HIV (non-AIDS) (\$19,650 compared to \$10,600). As expected, payments for enrollees with AIDS were substantially higher than for enrollees with HIV (non-AIDS) (17 percent higher for dual enrollees; 40 percent higher for Medi-Calonly) (Figure 4). We speculate that expenditures for those who are dually enrolled are higher that those with Medi-Cal-only, even when taking into consideration disease stage, because Medicare's reimbursement rates to providers are higher than Medi-Cal's and, in general, dual enrollees may be sicker than Medi-Calonly enrollees, thus requiring more services and utilizing more expensive services (e.g., inpatient care and prescription drugs).

As Figures 3 and 4 show, there is little difference in Medi-Cal's expenditures for dual enrollees as compared to Medi-Cal-only enrollees. While Medi-Cal paid \$16,900 annually for Medi-Cal-only enrollees, Medi-Cal payments were \$956 higher for dual enrollees. Controlling for disease stage, Medi-Cal payments for dual enrollees with HIV (non-AIDS) were \$350 less than for Medi-Cal-only enrollees, while for dual enrollees with AIDS, Medi-Cal payments were \$1,041 more than for Medi-Cal-only enrollees. The relatively slight difference in Medi-Cal

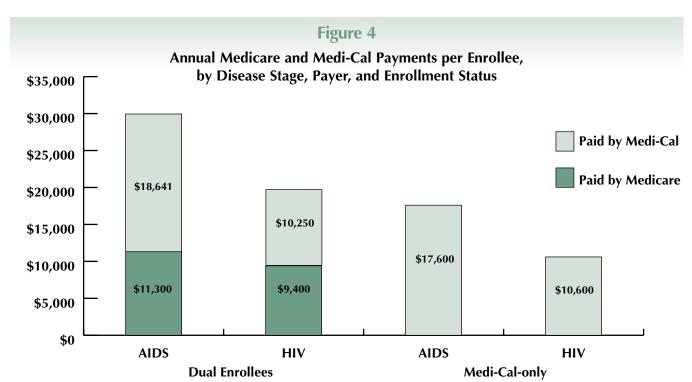
Figure 3 Annual Medicare and Medi-Cal Payments per Enrollee, by Payer Enrollment Status



Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.

expenditures for Medi-Cal-only and dual enrollees may be explained, in part, by the large share of MediCal expenditures for prescription drugs (Figure 5). The difference may be more substantial for those with AIDS than for those with HIV (non-AIDS), because as enrollees become sicker, they typically have higher prescription drug costs and use other services for which Medi-Cal is the primary payer (e.g., long-term nursing home services).

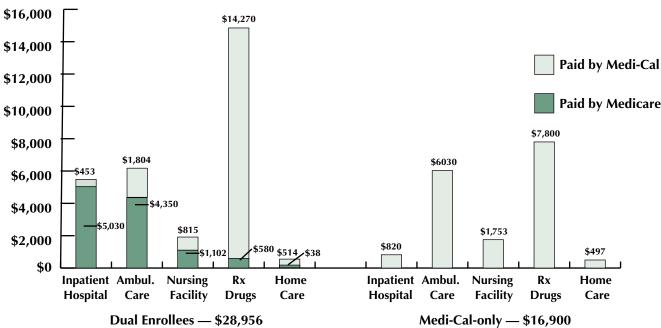
The division of expenditures between Medicare and Medi-Cal for dual enrollees varied sharply by type of service (Figure 5). Inpatient, ambulatory, and nursing facility service (including skilled nursing, rehabilitation, long-term care, and some hospice) expenditures were paid mainly by Medicare; prescription drugs were paid predominantly by Medi-Cal. Medi-Cal paid almost all (96 percent or \$14,270 per person) of dual enrollees' combined Medicare-Medi-Cal prescription drug payments. Home care costs, including home health, home nursing, and home and communitybased services, were also paid mainly by Medi-Cal (93 percent or \$514 per person). Medi-Cal also covered 30 percent (\$1,804) of the combined programs' payments for ambulatory care; 43 percent (\$815) of nursing facility service payments; and 8 percent (\$453) of payments for inpatient services. These patterns reflect differences in services covered under the two programs.



Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.







Source: National Academy of Social Insurance analysis of Medi-Cal claims data from California's Department of Health Services.

Medi-Cal's payment for prescription drugs is important to HIV/AIDS treatment and is crucial to dual enrollees. By covering nearly all of the combined Medicare-Medi-Cal prescription drug payments made on behalf of dual enrollees, Medi-Cal paid more per person for prescription drugs (\$14,270) than the total Medicare payment for services (\$11,100). In addition, dual enrollees had almost twice the combined programs' prescription drug expenditures as those on Medi-Cal-only. Higher drug spending for dual enrollees may be attributable to dual enrollees being sicker and/or having more established and expensive drug regimens. It is also possible that dual enrollees have higher drug expenditures because Medicare providers may prescribe more drugs and/or more expensive drugs than Medi-Cal providers.

Aggregate payments by Medicare and Medi-Cal, and the federal and state share for the care of California dual enrollees living with HIV/AIDS in the fee-for-service system were:

 Medicare and Medi-Cal payments totaled \$177 million (includes federal and state).

- Medicare paid \$68 million (38 percent).
- Medi-Cal paid \$109 million (62 percent).
- Federal Medicare-Medi-Cal payments for the dual enrollees totaled \$124 million (70 percent of total).
 - The largest share of federal payments was \$68 million from Medicare (55 percent).
 - \$56 million represented the federal share of Medi-Cal payments (45 percent).
- The state of California's share of the Medi-Cal payments was \$53 million (32 percent of total).9

Policy implications

This analysis provides information for policymakers to consider when evaluating the need for change in federal and state health coverage programs. To better support people living with HIV/AIDS and other chronic conditions, when making Medicare reforms, policymakers should consider:

- The implications of expanding Medicare's benefit package, thus shifting costs between Medicare, Medicaid, and other payers. Numerous proposals to broaden Medicare's benefit package have been hampered by projections of the increased costs to Medicare. The projected increase to Medicare should reflect the fact that the federal government is already paying a substantial amount for Medicare enrollees' health care coverage through Medicaid and other federally funded programs. The federal government currently pays about half of California's Medicaid expenditures for dual enrollees. The incremental cost to the federal government of adding additional Medicare benefits presently covered by Medicaid would be considerably less than the full cost of the benefits. Costs of adding a drug benefit to Medicare, for example, would be less than the full cost of the benefit, because the federal government is already paying a significant share through Medicaid. Nonetheless, such shifts in coverage for dual enrollees have implications for both federal and state budgets. Also, because Medicare and Medicaid are entitlement programs (they are automatically funded each year, with major funding changes made only through a change in law by Congress or regulation issued by the Executive Branch), a shift in benefit coverage to or from programs funded by discretionary funds (those that receive yearly appropriations by Congress), namely the Ryan White CARE Act and its AIDS Drug Assistance Program (ADAP), involves trading entitlement spending with discretionary spending.
- **How the dual Medicare-Medicaid funding streams affect efficiency. Policymakers should consider whether administering two separate programs to meet the health care needs of chronically ill people results in inefficient spending and unnecessary fragmentation of health care delivery. This analysis shows that combined program spending for dual enrollees was significantly higher than for Medi-Cal-only enrollees. Key reasons for these differences are the significant differences in payment rates between the two programs and the differences in enrollee health that affect the amount and intensity of service use.

- Some of the increased spending, however, probably reflects inefficiencies in the delivery and payment for services resulting from the need to coordinate differences in covered benefits, participating providers, and payment methods and amounts.
- From the point of view of Medicare enrollees and providers, how well the dual payers and programs coordinate. The National Academy of Social Insurance has documented the difficulties that Medicare enrollees with HIV/AIDS have coordinating their Medicare coverage with that of other payers.¹⁰ The analysis described in this *Medicare* Brief confirms that dual enrollees are dependent on Medicaid for a large share of combined Medicare-Medi-Cal expenditures, with most of the payments for prescription drugs and significant portions of ambulatory, nursing facility, and home care services paid by Medi-Cal. Though most enrollees and providers know that Medicare does not cover outpatient prescription drugs, when and why Medicare pays for ambulatory care, nursing facility care, and other categories of services covered by both programs can be unclear and confusing. The addition of benefits that Medicare does not currently pay for would relieve the programs and their enrollees of the need to coordinate the multiple payers' benefits and payments, reduce enrollees' need to find and coordinate supplemental insurance, and promote a more coordinated care system.

Agenda for future research

This analysis of California's Medi-Cal data file is a first step in examining financing from both Medicare and Medi-Cal for dual enrollees with HIV/AIDS. Further examination of the costs and financing of care for Medicare beneficiaries in conjunction with other payers is necessary for informed policymaking. The reasons why programs' dual enrollees cost almost twice as much as those on Medi-Cal-only need to be studied. Little is known about dual enrollees' utilization of services and whether enrollees move on and off these programs or have stable, continuous coverage. Information is also lacking about those with HIV/AIDS or other chronic conditions who are enrolled in Medicare but not Medicaid, and those enrolled in a Medicare and/or

Medicaid HMO. Valuable information could be gained by linking multiple payers' databases (e.g., Medicare with Medicaid) and linking program databases to related surveys such as the HIV Cost and Services Utilization Survey (HCSUS).

Endnotes

- 1 Recipients of Social Security disability benefits include three categories of disabled individuals. Disabled workers become eligible based on their own work in employment covered by Social Security. Disabled widow(er)s age 50 and older become eligible for survivor benefits based on a deceased spouse's work record. Disabled adult children become eligible as the dependent of a parent who is retired, disabled, or deceased.
- 2 In 2000, Medi-Cal's monthly income limit was \$620; asset limit was \$2,000.
- 3 For those with insurance obtained through an employer with less than 100 employees, Medicare is the first payer and the employer-based insurance is the second.
- 4 As of June 30, 2000, U.S. Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report.
- 5 Classification of AIDS based on indicative diagnostic and/or drug codes during the 1996-98 period. AIDS classification included those with ICD9-CM diagnostic codes 042.x or 042 and codes for opportunistic infections that satisfy CDC AIDS surveillance criteria and/or National Drug Codes for drugs used only for these opportunistic infections.
- 6 Based on authors' discussions with HCFA Region IX Medicaid HIV Coordinator, AIDS Project Los Angeles benefits staff, and a private benefits consultant based in Los Angeles.
- 7 Eligibility for CalWORKs, California's public cash assistance program, meets Medi-Cal's eligibility requirements. CalWORKs bases eligibility on depri-

- vation to a needy child, property, income, residency in California, and age of children.
- 8 Annual cost per enrollee was calculated by summing enrollees' costs during 1998 and dividing by the total enrollee-years of Medi-Cal participation during 1998. Duration of participation is defined as the elapsed time between the first and last service claim during the year, plus 30 days to reflect the typical duration between services, to a maximum of 12 months. All per enrollee payments are the average of all enrollees in the data file.
- 9 The federal share of Medicaid costs for FY 2001 is 51.25%; the state of California's share of Medicaid costs is 48.75%.
- 10 See NASI Medicare Brief No. 7, Coordination of Health Coverage for Medicare Enrollees: Living with HIV/AIDS in California, by June Eichner.

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