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Public Funding of HIV/AIDS Prevention, Treatment and Support in California

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Abstract

Objectives: To determine the amount of public financing for HIV/AIDS in California, and its distribution among treatment, prevention and support services. To determine the geographical distribution of public financing for HIV/AIDS within California.

Design: Data on HIV/AIDS expenditures were compiled across federal and state agencies supporting HIV/AIDS in fiscal year 2008.

Methods: Federal and state data on programs that finance HIV/AIDS treatment, prevention and support services, including the Ryan White Program, the Centers for Disease Control and Prevention, and the California General Fund, were compiled. California-specific expenditures for Medicare and Medicaid were calculated from claims data. Other entitlement program spending was estimated from national HIV/AIDS data. Data on AIDS cases by county were obtained from the California State Office of AIDS. Mapping to California counties was accomplished with Arc-GIS software.

Results: Public funders accounted for approximately $1.92 billion in HIV/AIDS services in California in fiscal year 2008. Most (90.4%) supported treatment; prevention accounted for 6.4% and support services for 2.6%. The majority of treatment financing came from two Federal health entitlement programs, Medicare (36%) and Medicaid (28%). Counties with the highest case loads had lower expenditures per case, suggesting economies of scale.

Conclusions: Treatment expenditures overshadow prevention spending. The dominance of entitlement programs in funding for HIV/AIDS treatment challenges policy-makers to monitor the extent and quality of HIV/AIDS care in California. A unified health information system for HIV/AIDS that bridged the fragmented health payment system's data silos would benefit policy makers' efforts to monitor the delivery of HIV/AIDS services.

Keywords

HIV; health policy; state health planning, United States; information systems; financing

Introduction

The National HIV/AIDS Strategy for the United States [1] calls for greater "coordination of HIV programs across the Federal Government and between Federal agencies and State,

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territorial, local, and tribal governments." Currently, it is even difficult to determine even the total amount of funding devoted to HIV/AIDS across these levels of government. Although estimates of the level of federal support budgeted for HIV/AIDS ($19.4 billion for fiscal year 2010 [2]) are readily available, state-specific estimates of public spending on HIV/AIDS are not. Such estimates are vitally important, however, because states and localities play a major role in managing the federal support for HIV/AIDS, which derives from a variety of agencies, including the Health Resources and Services Administration (HRSA), Center for Disease Control and Prevention (CDC), Substance Abuse and Mental Health Services Administration (SAMHSA) and the Department of Veterans Affairs (VA). States also allocate state general fund revenues for HIV/AIDS treatment, support and prevention services.

At the state level, several factors make it difficult to determine public financial support for HIV/AIDS. First, states receive a large number of public funding streams for HIV/AIDS services. Some Federal funding for HIV/AIDS is provided directly to highly impacted areas, such as Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs); other federal funding is provided to state agencies that allocate it to health jurisdictions within the state. Some states support HIV/AIDS services directly from their General Funds. Additional funding can be designated by other state-level departments—such as the Departments of Corrections, Social Services, or Mental Health—for HIV-specific services.

Second, a large share of federal financing of HIV/AIDS ($12.1 billion in fiscal year 2010) is delivered by entitlement programs, such as Medicare and Social Security, where benefits are accessed directly by the individual, and are not easily monitored by states. [2]

Third, the complexity of treating HIV means that persons living with HIV/AIDS (PLWH) may be receiving services in multiple locations from different providers, supported by various funding streams, with varying eligibility criteria and reporting requirements.

Finally, these funding streams may change over the course of the disease. For example, HRSA's CARE/HIPP program may subsidize continuation of employer-based health insurance that would otherwise be lost when a PLWH leaves employment. If disabled and low income, a PLWH may qualify for Medicaid, and, after two years of disability, may qualify for Medicare.

These multiple payment sources make it challenging for state health care planners and policy makers to obtain the data necessary for a comprehensive picture of financing of HIV/AIDS services. Knowing the levels of public financial support for HIV/AIDS is important for state planning efforts because many PLWH rely on public funding for the care, treatment, and support services they need. The number of PLWH relying on public programs has grown in the recession and will further expand in the future because health reform renders many non-disabled persons eligible for Medicaid. The changing demographics of the epidemic reinforce this trend since with increased longevity attributable to antiretroviral therapy (ART), more PLWHA are eligible for public programs such as Medicare and because an increasing share of new HIV infections occurs among lower income groups and among racial and ethnic minorities, who are less likely to have private insurance coverage. [3]

In 2007, California leaders in HIV/AIDS policy, service delivery, and research sought to better inform planning and decision making for HIV/AIDS services by compiling comprehensive data on federal and state support of HIV/AIDS programs in order to address a number of fundamental questions:

--- What is the level of support for HIV/AIDS in California provided by the full spectrum of public funders?

--- What are the shares of treatment, support and prevention services in total HIV/AIDS public funding?

--- How are expenditures on HIV/AIDS distributed geographically across California?

--- Are expenditures on HIV/AIDS proportional to case loads?

This article reports on the development of a comprehensive assessment of public funding for HIV/AIDS services in California. Following this introduction, the methods used are presented, followed by results. We conclude with a discussion of the implications of the findings for HIV/AIDS planning and for future data collection efforts.

Methods

HIV/AIDS Expenditure Data

The amounts of funding for HIV/AIDS treatment and support were compiled from the major federal and state agencies supporting HIV/AIDS in the fiscal year 2007/08 (FY08). Prevention funding was obtained from the CDC and by abstracting state contracts. [4] We assigned funding to the local health jurisdiction (LHJ) in which it was used. Appendix Table A details the sources of expenditure data for the public agencies included in the analysis. When data were available only for a prior year, the amounts were adjusted for program growth and prices, using the medical Consumer Price Index (CPI). [5]

National entitlement programs such as Medicare do not publish state-specific estimates of funding for HIV/AIDS. However, we obtained from the Center for Medicare and Medicaid Services, medical claims data for all Californians in the two programs who were identified by diagnosis or medication use as having HIV/AIDS. From these claims data, the authors calculated Medicare and Medicaid expenditures on medical treatment and medication for all Californians with HIV/AIDS enrolled in fee-for-service (FFS) Medicare or in FFS or managed care Medicaid in 2007.

The number of AIDS cases in each county was obtained from the California State Office of AIDS. [6] We did not use numbers of non-AIDS HIV cases, because in 2008 the state was still in the process of developing a comprehensive count, following the introduction of names-based reporting of HIV in 2006. [7]

VA expenditures on HIV/AIDS are also not published by state. Nationally, the VA is estimated to have spent $639 million on HIV/AIDS care in FY08. [2] To estimate VA spending on HIV/AIDS in California, we applied the percentage of all VA medical care expenditures in California ($3.01 billion out of a national total of $31.88 billion, or 9.4%). [8] To estimate the number of California veterans with HIV/AIDS served by the VA in 2008, we multiplied California's share of all veterans by the estimated 23,000 veterans with HIV/AIDS served nationally by the VA. [9]. Drug costs were estimated by multiplying this number by average annual drug costs for PLWHA, estimated from data for the California AIDS Drug Assistance Program (ADAP). [10]

Allocating Expenditures to Health Jurisdictions

It is important to understand not only the total amount of funding, but also how the funding for treatment, prevention and support is distributed across the state. Medicare and Medicaid expenditures were summed to the county level for both fee-for-service and managed care enrollees. Subjects with missing data on county were assigned to counties proportional to the county's share of AIDS cases.

We had only state-level estimates of HIV spending for ADAP and the VA, which provide services directly to patients who, in turn, choose which facility to use. In these cases, we allocated the total estimated funding for HIV/AIDS to California counties in proportion to the number of living AIDS cases.

Analysis

We tabulated total public spending in California for each category of service: treatment, pharmaceuticals, prevention and support within each county. All data were checked for inconsistencies and verified with the funders, where possible.

To determine how total public HIV/AIDS funding was distributed across California, ArcGIS technology was used to map both total amounts of funding and funding per living AIDS case. To preserve confidentiality of the Medicare and Medicaid data, we combined low-prevalence counties into nine aggregate groups, yielding 27 jurisdictions in total.

Results

Total Public Funding

We estimate that public sources of funding accounted for approximately $1.92 billion worth of services for HIV/AIDS in FY08 (Table 1). Treatment accounted for 90.4% (42.3% for medical care and 48.1% for pharmaceuticals), while 6.4% was spent on preventive services, 2.6% on support services, and less than 1% on other services. Historically, California has made substantial General Fund allocations to supplement federal funding for HIV/AIDS care.

Treatment and Pharmaceutical Funding

Two public insurance programs—Medicare and Medicaid—account for the majority of funding for HIV/AIDS treatment in California. Medicare covered over 20,000 PLWH in California in 2007 at a cost of $625.8 million, or $30,911 per enrollee. Medicaid served nearly 33,100 PLWH in California in FY08 at a total cost of $493.5 million. The average Medicaid cost per enrollee of $14,916 includes both the costs for PLWH who do not also have Medicare coverage (with average costs of $19,779), as well as the lower average Medicaid costs for dual eligibles ($7,212), whose primary insurance is Medicare. We estimate that there were 2,070 veterans with HIV/AIDS who sought care at the VA in FY08 at a cost of $60.32 million, or $29,140 per capita.

Table 2 shows that Medicare accounts for 36.1% of public funding of HIV/AIDS treatment and pharmaceutical spending in California, while Medicaid accounts for 28.4%. ADAP accounts for 5.1% and other Ryan White programs for 7.0% of treatment funding. The Department of Veterans Affairs accounts for an additional 3.5% and State General Funds allocated by the CA Office of AIDS and other state agencies, such as the Department of Corrections, account for 19.9% of HIV/AIDS treatment.

Prevention Funding

The CDC provides the majority of publicly supported prevention funding in California. The $62 million that the CDC provided directly to various California health jurisdictions accounted for 50.4% of total prevention funding for FY08. The remaining half was distributed by the CA Office of AIDS and included allocations from both CDC and from the state General Fund. CDC support to the state for Counseling and Testing (C&T) accounted for 8.5% of prevention funding while CDC allocations to the state for Health Education and Risk Reduction (HERR) accounted for 29.8% of all prevention funding. The California Departments of Education and Alcohol/Drugs provided 0.3% and 10.2% of total prevention

funding respectively, while Ryan White funds designated for prevention services represented 0.9% of prevention funding.

Support Funding

Ryan White Part A funds specifically for support services made up 36.8% of total support funding. SAMHSA block grants and discretionary grants awarded directly to health jurisdictions in support of mental health and substance abuse services accounted for approximately 51% of total support funding. [11] The California Departments of Mental Health and Social Services accounted for 3% and 0.4% of total support funding, respectively. Funding for housing accounted for almost 9% of the support budget, with 1.9% coming from the state-funded Resident AIDS Licensed Facility (RALF) housing program and 7% coming from the federally-funded Housing Opportunities for Persons with AIDS (HOPWA) program.

Other funding included Epidemiology/Surveillance funds from both the CA Office of AIDS (78%) and federal sources (14%), as well as federal funds designated for planning and technical assistance (8%).

Data Mapping

Figure 1 shows the distribution by county of total HIV/AIDS funding (top panel) and funding per AIDS case (bottom panel), with darker colors representing higher levels of public financing for HIV/AIDS services.

Mirroring the distribution of AIDS cases, funding is highest in Southern California counties, in the San Francisco Bay area, and in Sacramento County. However, the per capita spending levels reveal a nearly reverse pattern, with lower spending per AIDS case in counties with the highest case loads and highest per case spending in counties with the fewest cases. This pattern suggests that there are economies of scale in delivering treatment and support services. The rural jurisdictions had higher than average spending on pharmaceutical, prevention and support services per case, but their HIV/AIDS treatment costs per case were lower than the California average. PLWHA in rural areas may seek treatment in facilities outside their local area, or medical costs may be lower in these counties.

Discussion

The macro-level view of public HIV/AIDS funding in California yields two important findings. First, federal entitlement programs account for a large share of public HIV/AIDS funding; second, a relatively small percentage of total public funding (6%) is devoted to prevention.

Medicare and Medicaid dominate Ryan White funding for HIV/AIDS treatment

Although Ryan White funding is central in the state's planning for HIV/AIDS treatment delivery to the uninsured, the Ryan White treatment funding level of $210 million in FY08 is dwarfed by Medicare and Medicaid treatment expenditures, which accounted for more than $1.1 billion in HIV/AIDS-specific funding in California in the same period. However, the Ryan White funding is critically important for the uninsured, including those who are not eligible for Medicare and Medicaid. Specifically, the Ryan White program has a large role in providing support for pharmaceuticals through the ADAP program.

Despite the magnitude of funding for HIV/AIDS supplied by Medicare and Medicaid, the services delivered by these programs have not been extensively examined. [1] This is the first study to examine the levels of Medicaid and Medicare spending on HIV at the state

level. We estimated that Medicare spends nearly $31,000 per enrollee with HIV annually and the V.A. spends $29,140 per capita, figures that are consistent with the average spending level for a comparable population: persons with CD4 counts less than 200 cells/ μl, whose costs at three large HIV specialty clinics averaged $29,912. [12]

Prevention services account for a small percentage of total HIV/AIDS funding

Prevention services accounted for approximately 6% of total public funding for HIV/AIDS in the state of California in FY08. Although a relatively small percentage was spent on prevention, California's prevention expenditures exceeded the national average, where the percentage of HIV/AIDS spending devoted to prevention is only 4%. [2]

Unfortunately, the amount of public funding available in California for HIV/AIDS prevention fell in FY10 due to the state's elimination of General Fund support for HIV prevention. The result is that total resources available for HIV education, prevention and testing fell from $42.4 million in FY09 to $12.2 million in FY10. [13]

Limitations—The fragmentation of financing and delivery of HIV/AIDS treatment, pharmaceutical, prevention and support services means that this analysis may have missed some sources of spending. In particular, we lacked data on treatment costs for Medicare recipients enrolled in managed care. In the course of our research, we identified additional sources of public funding for which we were unable to document HIV/AIDS-specific expenditures. For example, school systems spend some of their own resources on HIV/AIDS prevention efforts, but we were unable to obtain reliable estimates of those amounts. We are convinced, however, that we have captured the vast majority of public expenditures on HIV/AIDS services in California, and that omissions are small relative to the amounts for which we have data.

In addition, we had only aggregate national estimates of HIV/AIDS spending by the VA, thus assumptions were necessary to estimate HIV expenditures in California. Our assumption that VA funding for HIV is proportional to California's share of the veteran population is conservative. Although California has a disproportionate share of PLWH relative to population, many are undocumented and not eligible for VA services. [9]

Historically, California has provided substantial amounts for HIV/AIDS from its General Fund; thus, particulars of the California findings may not generalize to other states. However, the need for a comprehensive data system is an issue for all states.

In conducting this research, we encountered a number of barriers to obtaining a comprehensive and accurate picture of public financing of HIV/AIDS services in California. These included:

1) Multiple data sources for the financing of a single type of service (e.g. information on CDC direct funding of health jurisdictions was not integrated with CDC funding to the state);

2) Lags in obtaining data on expenditures; and

3) Lack of information on the geographic distribution of funding for ADAP and VA services.

The multiplicity of funding streams makes it difficult for California decision-makers to obtain a comprehensive picture of the state's resources available for HIV/AIDS prevention, treatment, and support, which is essential for adequate planning and budgeting, at both state and local health jurisdiction levels. The allocation to health jurisdictions of the 2009 budget cuts to HIV/AIDS programs previously supported by the State General Fund, required the

CA Office of AIDS to have an accurate assessment of funding levels that EMAs, TGAs and demonstration sites in other jurisdictions received directly from HRSA and from the CDC. In addition, knowing the distribution of public support for HIV/AIDS across the state is crucial for understanding access to both HIV/AIDS care and prevention services in different localities.

Data systems for HIV/AIDS should integrate the funding received at the state level with that received at the local level. Information about funding that goes directly to local health jurisdictions is particularly important to state policy makers because the jurisdictions that receive direct funding from HRSA and CDC are those that have the greatest numbers of HIV/AIDS cases and therefore are critically important to the delivery of HIV services.

Retrospective data collection, on which this study had to rely, is inherently challenging because agencies that deliver HIV/AIDS services are overburdened, often underfunded and have difficulty retrieving data after the fact on numbers and types of services, staffing and their clients. States should strive to integrate data collection mechanisms into the day-to-day operation of their grantees.

California has implemented the AIDS Regional Information and Evaluation System (ARIES), to capture information on HIV/AIDS treatment services provided by most California agencies receiving state funding for HIV/AIDS. ARIES provides for real-time transfer to the state of information on each encounter. However, the state has little information on the attributes of HIV treatment funded by two public payers, Medicare and the VA, that account for nearly 40% of HIV/AIDS treatment costs in California.

Integrating prevention services, which are not currently included in ARIES, into the same system would allow for more comprehensive state planning. A linked system could improve the effectiveness with which positive individuals are connected to care and facilitate assessment of quality of care. Indeed, integrating health financing data is a core recommendation of Health Systems 20/20, a U.S. Agency for International Development (USAID) effort to support developing countries' health systems.[14] USAID recommends that its grantees establish comprehensive health accounts in order to obtain "An increased use of evidence for decision making (that) is translated into an improved allocation of resources." [14]

Implementation of the Patient Protection and Affordable Care Act (ACA) is likely to further complicate coordinating HIV/AIDS care across programs financed from different sources. The ACA will extend Medicaid eligibility to many uninsured individuals living in poverty, without regard to disability status, thereby allowing many former Ryan White clients to obtain insurance. The ACA, while providing new opportunities, also moves many PLWH beyond the purview of state oversight. This will increase the state's difficulty in monitoring quality of care and linking patients to support services, such as housing assistance, which will continue to be needed. Monitoring the quality and continuity of care for patients who receive services in more than one system will be impossible without information systems that bridge the existing data silos.[15] HIV service providers, often funded by multiple agencies with different reporting requirements, would also benefit from uniform reporting systems. Indeed, one of the goals of the National AIDS Strategy is to standardize grantee reporting.

Conclusion

In summary, this article's attempt to gain a comprehensive overview of publicly funded HIV/AIDS services in California calls attention to the need for HIV/AIDS policy makers to consider the full range of programs supporting HIV/AIDS in their planning efforts. This task

will become even more challenging in coming years, as more PLWH obtain Medicaid and private insurance coverage. Yet, a comprehensive information system, similar to the model that USAID recommends for developing countries, is essential to effectively plan for HIV/AIDS service delivery.

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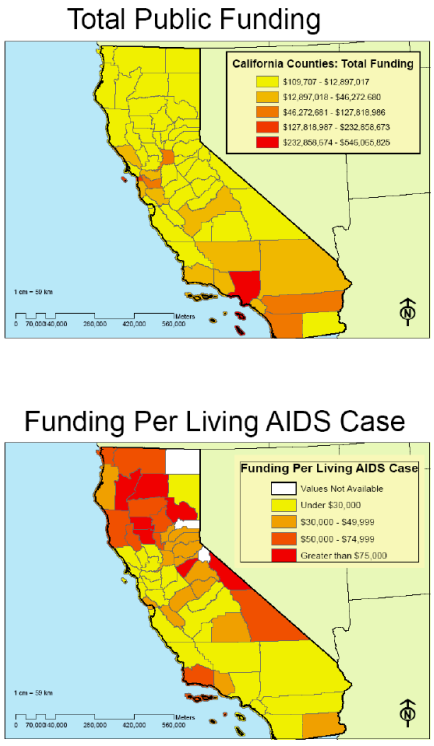

Figure 1.
Total Public Funding for HIV in California and Funding per PLWH (FY08)

Table 1

Total public funding for HIV/AIDS in California by Type (FY08)

	Total FY08	**Percent**
Total public funding	$ 1,919 million	100%
Treatment	$1,735 million	90.4%
Non-drug treatment	$ 812 million	42.3%
Drugs	$ 923 million	48.1%
Prevention	$ 123 million	6.4%
Support	$ 50 million	2.6%
Other	$ 12 million	0.6%

Table 2

Total public funding for HIV/AIDS Treatment in California By Source of Funding (FY08)

Funder	Treatment Costs	Pharmaceutical Costs	Total Costs	Percent
Medicare	$280.7 million	$345.2 million	$625.8 million	36.1%
Medicaid	$293.5 million	$199.9 million	$493.5 million	28.4%
State	$120.4 million	$224.1 million	$344.5 million	19.9%
Ryan White	$101.0 million	$21.0 million	$122.0 million	7.0%
ADAP		$88.5 million	$88.5 million	5.1%
Veterans Affairs	$16.1 million	$44.2 million	$60.3 million	3.5%
Percent of Total Costs	46.8%	53.2%		

Appendix Table A

Funding Categories and Sources of Information

Funding category	Source
Ryan White funding distributed by the state for treatment and support	The California (CA) Office of AIDS, HIV Care Branch funding matrix and Ryan White website
Treatment and support funding for Ryan White Part A grantees	HRSA website; verified with State Office of AIDS and EMA/TGAs
ADAP	State Office of AIDS and ADAP
Other state funding for PLWH	Departments of Alcohol and Drug, Mental Health, Social Services and Corrections; CA Department of Finance matrix
State Education and Prevention Allocations to from CDC and General Fund (Dept. of Education; Dept. of Alcohol and Drug; State Office of AIDS)	State Office of AIDS reports and abstraction of state contracts with particular counties and agencies
Prevention funding directed to LHJs	CDC “Domestic Awards,” 2008 website; data obtained directly from LA and SF
Mental health services	Substance Abuse and Mental Health Services Administration (SAMHSA)
Ryan White Part C and Part D	State Office of AIDS
Medicare	Authors’ Calculations Medicare claims files for 2007
Medicaid	Authors’ Calculations Medicare claims files for 2007