



*The Future of HIV/AIDS
Funding in California*

— Anne Donnelly and Dana Van Gorder

California has long been a model in its strong and innovative response to the HIV epidemic, particularly in the delivery of quality public HIV care. The level and quality of HIV care in the state is not a measure of the inherent strength of the national or California public health system; rather, it is due to the advocacy and personal commitment of a wide range of people, including people living with HIV/AIDS, their loved ones, advocates, medical and other care providers, scientific researchers, and elected and appointed officials.

As a result of this sustained effort, California has invested in the programs necessary to fill the gaps in a piecemeal public health system that was ill prepared to respond to such an overwhelming emergency. Today, however, the goal of assuring that HIV/AIDS services keep pace with growing demand is seriously threatened by the state's ongoing fiscal problems and a seeming lack of political will to address the domestic HIV/AIDS epidemic at appropriate levels.

The Scope of California's HIV/AIDS Epidemic and Current Government Spending to Address It

The HIV/AIDS epidemic continues to pose one of California's most serious public health challenges. As of September 30, 2003, 132,591 Californians have been diagnosed with AIDS; of those individuals, 78,771 have died. As many as 124,305 Californians may be living with HIV/AIDS, and it is estimated that some 8,000 to 9,000 individuals

in the state are newly infected with HIV each year. In 2002 alone, 2,332 new cases of AIDS were diagnosed in the state. California accounts for approximately 1 in 7 of all cumulative AIDS cases in the United States and has the second highest number of cumulative AIDS cases, second only to New York.*

The face of the AIDS epidemic in California differs from that of the rest of the country. To date, 78% of AIDS cases in California have occurred among men who have sex with men (MSM), including those who inject drugs. By comparison, this group represents 52% of the national epidemic. While non-MSM injection drug users represent 25% of the epidemic nationally, 11% of AIDS cases in California have been from this population. Cases transmitted through heterosexual sex account for 5% of California's epidemic, but 11% nationally. AIDS cases have occurred largely among whites in California: 59% compared with 42% nationally. African Americans accounted for 18% of cases compared with 38% nationally, and 21% have occurred among Latinos compared to 18% nationwide. Newly diagnosed AIDS cases have been rising steadily since 1993 among African Americans, while roughly holding steady among Latinos, Asians, and Native Americans and declining among whites. California's epidemic has largely occurred among men, with 92% of cases in this group compared with 82% nationally.

The HIV/AIDS public health care delivery in California is largely supported through Medi-Cal (California's

Medicaid program), the federal Medicare program, the AIDS Drug Assistance Program (ADAP), and other Ryan White CARE Act-funded programs. These programs work together to allow most Californians access to HIV care and treatment. California currently serves about 28,000 people with comprehensive care through Medi-Cal, the public health care safety net for those with low incomes. People with AIDS qualify for Medi-Cal by meeting Social Security Administration criteria for disability. California also maintains one of the most effective ADAP programs in the country, serving some 23,500 people. ADAP is a lifeline for people living with HIV, providing essential prescription drugs for low-income people who cannot otherwise afford treatment. In addition, the Ryan White CARE Act and state-funded programs provide primary medical care and necessary support services.

In the current 2003-04 fiscal year (FY), California will spend approximately \$949.1 million on HIV/AIDS programs, including Medi-Cal and ADAP. Of that amount, the state will contribute \$451.7 million; the federal government will contribute \$447.1 million; and rebates from pharmaceuticals purchased by ADAP will contribute \$50.3 million.

The Political Climate for HIV/AIDS in California

California's HIV/AIDS programs have benefited over the years from the strong political support of a state legislature consistently dominated by Democratic majorities, which have

* US figures were reported by the US Centers for Disease Control and Prevention (CDC) as of December 2002, except for estimate of HIV infections, which was reported in the Journal of the American Medical Association 1992, and the estimate of new infections per year, which was reported by the CDC in 1997. California figures were reported by the California Department of Health Services, Office of AIDS as of September 30, 2003, except for persons living with AIDS, which is the total estimated by the CDC as of June 30, 2000.

generally supported funding levels that keep pace with the epidemic's growth and policies that benefit people living with HIV/AIDS. In the past 13 years, the budget for HIV/AIDS programs, including ADAP, has grown substantially during the tenures of both Republican Governor Pete Wilson and Democratic Governor Gray Davis.

The recall of Governor Davis and election of Governor Arnold Schwarzenegger leave substantial questions about the future of HIV/AIDS funding and policy in California. Prior to his election, Schwarzenegger's views about HIV funding and policy issues were completely unknown. Now that he has begun to make proposals to address the state's ongoing budget deficit, currently estimated at \$14 billion for FY 2004-05, there is growing alarm about the potential for severe damage to California's high-quality system of HIV/AIDS care.

Initially, it appeared that moderate Democratic lawmakers might be intimidated by the new governor's popularity and media appeal, but in a high-stakes battle, the legislature has recently rejected key finance proposals from his administration that they view as harmful to health and human services programs. Still, while the Legislature could vote to increase support for HIV/AIDS programs in coming years, particularly ADAP, California's governors have "line-item" authority to cut expenditures that they do not support from the approved budget.

California's HIV Care Delivery Is Seriously Challenged

The California model of HIV care and treatment delivery is facing tremendous challenges that threaten to undermine access to comprehensive HIV care. If California's commitment to

these programs wanes, meaningful advances not only in the health of people living with HIV/AIDS but also in the overall public health could be reversed.

The challenges come from both the federal and state levels, and are occurring in the context of substantial increases in the demand for core health services. Currently, many newly HIV-infected Californians must rely on some portion of state-funded care services. Additionally, people living with HIV/AIDS in California are experiencing substantial increases in longevity. In 1992, the state was home to approximately 5,000 individuals living with AIDS. By 2002, thanks to improved therapies and care delivery, 50,000 Californians were living with AIDS. As the state prepares for FY 2004-05, in order to keep pace with the increasing number of people who will need medications through ADAP alone, the state will need to increase spending by an estimated \$45 million.

Assuring Full Funding for ADAP for Fiscal Year 2003-04

In the face of massive state budget deficits in both FY 2003-04 and FY 2004-05, advocates in California have made it their goal to maintain current levels of funding for all HIV/AIDS programs while securing funding increases for ADAP. For the past several years, ADAP has needed a significant increase in support to keep pace with a growing enrollment, the addition of effective but costly drugs to its formulary, and increases in the cost of those drugs. The California ADAP currently serves approximately 23,500 individuals. For FY 2003-04, ADAP is budgeted at \$212.3 million, of which the state will contribute \$66.5 million; the federal government will contribute \$99.5 million; and, as men-

tioned above, pharmaceutical rebates will contribute \$50.3 million.

To be sure, California's ADAP population is seriously disadvantaged economically, particularly in a state where the cost of living is extremely high. In 2002, 45.9% of ADAP clients earned less than \$8,860 annually; 31.4% earned between \$8,861 and \$17,720; 13.9% earned between \$17,721 and \$26,580; 7.2% earned between \$26,581 and \$35,440; and only 1.1% fell into the highest eligibility category earning between \$35,441 and \$50,000.

For FY 2003-04, it was necessary to increase the ADAP budget by \$28 million. Securing an increase of this size was a major challenge in the face of a \$38 billion state budget deficit. Governor Davis had to be persuaded to allow \$19.7 million from pharmaceutical company rebates to remain in the program as had traditionally been allowed. Additionally, advocates were placed in the reluctant position of agreeing to transfer \$7 million from the state's HIV Therapeutic Monitoring Program, which pays for viral load and resistance testing, to ADAP to assure full access to HIV medications. Counties have been asked to pick up the cost of the therapeutic monitoring at the local level, where possible, to provide for this important service. An additional \$2.3 million in ADAP-specific funding through Ryan White Title II came to California for FY 2003-04 as a result of an \$83 million Congressional increase for the program for FY 2003.

In addition, advocates defeated a proposal by Governor Davis to impose copayments on ADAP clients earning more than 200% of the Federal Poverty Level (FPL). When he released his draft budget in January 2003, Davis proposed to save ADAP \$7.2 million by

imposing co-payments of \$30 per prescription per month for individuals earning between \$17,960 and \$26,940 per year, \$45 for individuals earning between \$26,941 and \$35,920, and \$50 for individuals earning between \$35,921 and \$50,000 per year. (Currently, only ADAP clients in California earning more than \$40,000 per year are required to contribute co-payments.) He also sought statutory authority to permit ADAP to establish a waiting list to address the remaining \$20.8 million shortfall in the program. In May 2003, responding to community opposition, the Governor opted to reduce the proposed co-payment amounts to \$5, \$10, and \$15, but the Legislature also rejected this scheme at the urging of advocates.

Drug rebates have been an important source of revenue for ADAP. Recognizing the crisis facing state ADAPs, the National Alliance of State and Territorial AIDS Directors (NAS-TAD) brought together leading ADAP directors to negotiate with pharmaceutical companies for better drug prices for ADAPs. Michael Montgomery, the chief of the California State Office of AIDS, was one of the initiators of this ADAP Crisis Task Force, which was successful in making agreements with pharmaceutical companies to provide an additional annual savings to ADAPs nationwide of between \$60 and \$65 million. California's ADAP budget gap was bridged in part by additional rebate money last budget year. However, more will be needed to contribute to the shortfall facing the program in FY 2004-05.

Funding ADAP in FY 2004-05 Under a Newly Elected Governor

Shortly after taking office in November 2003, following the recall of Governor

Davis, Governor Schwarzenegger presented a proposal to cut \$1.9 billion in current FY 2003-04 spending to prepare for a budget deficit estimated at \$14 billion for FY 2004-05. If approved by the Legislature, these cuts would disproportionately affect important health and human services programs.

As part of these cuts, Schwarzenegger proposed to permanently cap ADAP enrollment at its current level of 23,500 effective January 1, 2004. Individuals who leave the program could be replaced with new applicants under his proposal, but if entry to and departure from the program remains consistent, some 120 people would be forced onto a waiting list each month regardless of their medical condition.

Governor Schwarzenegger's proposal to cap ADAP enrollment bodes poorly for advocates' requests for the estimated \$45 million needed to adequately fund ADAP in FY 2004-05. \$25 million of that increase is needed to fund growth and increased costs of the program, while another \$20 million is needed to replace one-time rebate revenue used to fully fund the program in FY 2003-04.

In order to reduce the burden on the state general fund, advocates, state officials, program administrators, and others have begun discussions to explore potential cost savings to the program. Since ADAP was centralized in 1997, data collection, distribution, and client access have improved dramatically. However, due to better understanding and control of the program, there may be mechanisms that could bring some additional savings to the program without affecting clients in any significant way.

Nevertheless, there will still be a need for additional state general funding to

meet the growing demand and increased cost for ADAP. The state has shown great commitment to this important program, recognizing it as an extremely effective tool in its response to the epidemic. Waiting lists or program cuts are both inhumane and shortsighted. People who cannot access appropriate treatment for HIV disease will only get sicker and ultimately could die. Already, people have died while on waiting lists in at least two states—Kentucky and West Virginia—that have been forced into that position. And even for those who are not in such precarious health, lack of treatment will result in more difficult and expensive health care needs. This program can and must be a priority for California, even in challenging fiscal years.

Two other proposals made by the Governor could significantly affect future funding for health and human services programs, including HIV/AIDS. First, to help him prepare his budget proposal for FY 2004-05, Governor Schwarzenegger has asked all departments of state government, including the State Office of AIDS, to identify up to 30% in cuts to state spending. In the case of discretionary programs, this could result in a cut of as much as \$49 million to HIV/AIDS programs. Schwarzenegger has also proposed to finance \$15 billion in existing state debt using revenue bonds. Should voters ultimately not approve these bonds, this sum would have to be cut from current programs on a one-time basis.

California's Budget Problems Are Exacerbated by Washington's Lack of Focus on Domestic HIV/AIDS Issues

As with virtually every other state in the nation, California's HIV/AIDS serv-

ices would not be so severely threatened if an appropriate amount of funding were forthcoming from Washington. Although it deserves credit for recognizing the importance of funding global HIV/AIDS programs, the Bush Administration and Congress have shown little commitment to addressing growth in the domestic epidemic. Funding for the Ryan White CARE Act has been virtually flat for the last 2 years, despite growing need. Medicaid has come under attack from the Administration as attempts are made to limit federal contributions to the program. The Administration strongly backed the Medicare Prescription Drug Benefit, which is likely to reduce current prescription drug coverage for some of the poorest and sickest Medicare beneficiaries, including many people living with AIDS. The bottom line is that the Bush Administration and Congress appear to be leading the federal government into a rapid retreat from its commitment to provide health care to some of the most vulnerable uninsured and underinsured Americans.

Federal Funding of Discretionary HIV/AIDS Programs Is Not Meeting Growth in the Epidemic

Although the Ryan White CARE Act, which includes ADAP, is looked to as a payer of last resort, filling gaps left by other programs, it is a discretionary program. This means that it must be funded each year by the Administration and Congress through a highly competitive appropriations process and receives no automatic funding increases based on growing need. Funding for the CARE Act is based entirely on political will and the amount of discretionary funding Congress has in its various domestic accounts. Although funding for CARE programs has grown from \$220 million in 1991 to just over \$2 billion in 2003,

it has never fully funded the true needs posed by the epidemic.

Sadly, FY 2004 is shaping up as the worst year so far for federally funded domestic AIDS programs. Tax cuts, Iraq and Afghanistan war spending, the economic recession, and the Bush Administration's continued refusal to support increases in its budget for domestic AIDS programs have all contributed to the poor outcome. After a scare in the House, where CARE Act programs were actually cut for the first time in history, the Senate restored most funding, although Title II has been cut by \$1.6 million. In the face of a growing epidemic, slightly decreased or flat funding translates to significant cuts.

The only glimmer of success was a small ADAP increase in the face of a huge shortfall. The budget bill for 2004 is likely to provide only \$38.6 million of the \$214 million needed to eliminate waiting lists across the country for ADAP clients. Of that amount, California will see approximately 5% or \$1.9 million—far below what is needed to address the program's \$45 million shortfall for FY 2004-05. The federal budget bill provides for flat funding of virtually all of the CARE Act, HIV prevention, and the Minority HIV/AIDS Initiative.

Adding to California's problems with shrinking federal contributions is the fact that the formula used to allocate ADAP funding to states has underestimated California's actual number of people living with AIDS by about 30%. The final FY 2003 federal increase for national ADAPs was \$83 million. Based on the actual number of reported AIDS cases, California expected to receive approximately \$8 million. However, the formula ultimately allocated only \$2.3 million, leaving the program with a shortfall of \$26.7 million.

The Recent Medicare Prescription Drug Bill Could Add to ADAP's Problems

Much attention has been focused on the recent approval by Congress and the President of the first prescription drug benefit for Medicare-eligible individuals. The bill, which takes effect in 2006, requires Medicare patients to receive their prescription benefits from private entities, which may be permitted to limit the number of drugs within any class of medications. In addition, there are significant cost-sharing obligations and gaps in the benefit, which would require a beneficiary to pay out of pocket for their drugs. Most significantly affected will be people who are "dual eligible" for Medicaid and Medicare. There are 6 million dual-eligible people in the United States, including 50,000 people living with AIDS, and they represent the sickest and the poorest Medicare beneficiaries.

Until now, dual-eligible people could access comprehensive service by combining their Medicaid and Medicare coverage. Under the Medicare prescription drug benefit bill, Medicaid will be prohibited from providing "wrap around" coverage for dual-eligibles, actually reducing their access to a comprehensive treatment regimen and leaving them entirely dependent on an inadequate Medicare prescription drug benefit. These gaps in the Medicare prescription drug benefit could represent an additional cost to state ADAPs unable to meet even existing demand. The potential cost to California of this gap in the Medicare coverage has yet to be calculated, but it could be substantial.

Medi-Cal Services for People with AIDS Could Be Seriously Limited in Future Years

Medicaid is currently an entitlement program, meaning that the state and

federal governments are required to pay for all those who qualify for its coverage. The states and federal government share equally in the cost of the program. Medicaid provides both mandatory and optional benefits, and each state Medicaid program has a great deal of flexibility in setting the scope of its benefit package and determining who qualifies for coverage. During times of fiscal crisis, many states resort to cuts in optional services or eligibility categories in the Medicaid program. Last year, the Kaiser Family Foundation reported that 49 states were considering cuts to their Medicaid programs.

In his budget proposal for FY 2003-04, Governor Davis proposed ending 18 “optional benefits” for Medi-Cal recipients including dental services, durable medical equipment, and some forms of home health care. These benefits were not cut in the final version of the budget approved by the Legislature, but the proposal certainly set the stage for future proposals of a similar nature. Governor Davis also proposed cutting back an “optional” expansion in eligibility for the Aged and Disabled waiver. Again, this proposal was not adopted, but could very well be introduced again in the upcoming budget struggle. This proposal would again have a serious negative impact on ADAP, which would have to struggle to cover the increased costs of those estimated 5,000 or so Californians living with AIDS impacted by the reduction in eligibility.

California has also embarked on cutting payments to health care providers for their services to Medi-Cal clients. The Legislature approved a 5% rate cut in FY 2003-04; however, a recent ruling by the courts that such a cut is illegal is likely to be

appealed. Governor Schwarzenegger is seeking an additional reduction of 10% for the period from January 1 to June 30, 2004. It seems a safe bet that this reduction could be continued, if not deepened, in FY 2004-05. While many community clinics may be able to afford to see patients at these reduced rates, other providers are not likely to do so, particularly in areas of the state that are lacking in community providers. As a result, it may be extremely difficult for some people with HIV/AIDS to obtain primary health care.

Early in 2003, the Bush Administration made an unsuccessful attempt to secure congressional approval to cap or “block grant” Medicaid payments to the states. This proposal would have established a maximum amount Washington would provide to the states for Medicaid services, adjusted only for some cost-of-living increases. It would also have provided the states with more “flexibility” to decide whom they would serve and with what benefits. Needless to say, a cap would have made it difficult to serve new Medicaid enrollees, respond to emerging health emergencies, or provide up-to-date standard of care to current enrollees unless states provided the additional money. Such a cap would also have made it virtually impossible to expand Medicaid to non-disabled people with HIV disease.

The nation’s governors came to a stalemate around the Bush proposal as many recognized the burden a cap would place on states to meet the cost of medical care for low-income people. Members of Congress and the Administration are discussing block grants for Medicaid once again, and it is very likely that it will be an issue in the next session of Congress.

Additional Factors That Could Affect HIV/AIDS Program Costs in California

Clearly, there are many challenges to ensuring the ongoing strength of California’s system of HIV/AIDS care. In addition, there are variables that could stress the care system even more than is already anticipated.

HIV Case Reporting

In July 2002, California implemented its first system for reporting cases of HIV infection. AIDS cases have been reportable since 1983, but the state wrestled for many years with the question of whether and how to report HIV cases. The system now in place reports cases using a confidential, non-name-based code that includes a computer-generated “soundex,” or numerical code, based on letters of the individual’s last name, date of birth, gender, and last 4 digits of his or her Social Security number. Positive HIV tests from anonymous test sites are not reportable under the new system; however, results of viral load tests that are indicative of HIV infection are reportable. Successful implementation of HIV case reporting is important for California, as it is for all states. By approximately 2007, distribution of Ryan White CARE Act funds will be based on the number of HIV and AIDS cases rather than AIDS cases, as is currently the case.

Once the full scope of the HIV epidemic is understood in each of the states based on full reporting, the need for additional funding of care services could become apparent. A more ominous problem is that the Secretary of Health & Human Services (HHS) must decide whether each of the state systems is accurate and reliable enough to allow distribution of CARE funds. To date, however, California and other states with non-

name-based codes have been unable to secure cooperation from HHS to satisfy questions about whether the systems can eliminate duplicate cases from state to state. Advocates in California will be pressing the Secretary for greater cooperation in order to avoid any future challenges to CARE funding.

Medi-Cal Expansion

Medi-Cal currently provides primary medical care and HIV medications for low-income people living with disabling AIDS and for a small number of HIV-positive people who enter Medi-Cal under other categories. Because Social Security Administration regulations do not define individuals with early HIV infection as “disabled,” thousands of low-income Californians with HIV disease are ineligible for Medi-Cal and are unable to receive primary health care through the program.

The US Centers for Medicare and Medicaid permits states to apply for a Medicaid waiver to extend health care coverage to people at all stages of HIV disease. Approval of the waiver requires a state to achieve cost-neutrality in a 5-year period (i.e., savings in health care costs must at least equal the combined federal and state expenditure for Medicaid). The San Francisco AIDS Foundation estimates that approximately 1,700 individuals could participate in such a program in California within 5 years of inception. In 2002, Governor Davis signed a law that requires the state to apply for a waiver to expand Medi-Cal to qualified people with HIV. The state’s Department of Health Services is responsible for developing the waiver application with active participation from HIV service providers and advocates. This process has been delayed by the rigors of the state’s budget process, but advocates are hopeful

that it can move forward. Medicaid provides comprehensive care and is also an entitlement, meaning that everyone who qualifies is served. Securing health care and prescription coverage for people with HIV/AIDS from entitlement programs is better than depending on a discretionary and less certain program.

Current Efforts to Encourage Additional HIV Testing

The US Centers for Disease Control and Prevention (CDC) has recently embarked on an initiative, Advancing HIV Prevention, which seeks to encourage people at risk to be tested for HIV, and it has been placing additional funding into testing programs. These programs include HIV rapid tests, which provide test results in only 20 minutes rather than 1 week, and were designed in part to address the problem that as many as 30% of individuals who test HIV positive never return for their test results.

The effort to encourage more testing is clearly one with benefits for individuals who may be HIV positive and do not currently know their status, as well as their sexual partners and children. However, the CDC must make commitments to coordinate with the Health Services and Resources Administration (HRSA), the administrators of the Ryan White CARE Act, and Center for Medicaid and Medicare Services (CMS) to ensure that those tested are linked to quality care. It must also join advocates in assuring that, if significant numbers of new cases of HIV infection are identified, the resources will be there to provide care and treatment for all those who test positive. There will be little incentive for high-risk individuals to heed suggestions about testing if it is widely known that the health care and prescription drug programs

that currently exist do not promise coverage for all those who need them. Additionally, the CDC must ensure that adequate prevention funding continues to support primary prevention efforts, particularly in the hardest hit communities in the epidemic.

Reviving AIDS Activism

Until now, California has been highly responsive to the financial and policy challenges posed by this ongoing tragedy. In the face of the monumental challenges that have been described here, building the political will to keep California’s public health care system ahead of growing demand for HIV/AIDS services will require a level of activism not seen in many years.

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