

# *The ADAP Funding Crisis: A Call to Action*

— William E. Arnold

Federal AIDS Drug Assistance Program (ADAP) appropriations were supported by the White House and Congress with open support from both political parties. Under Democratic and Republican White Houses and Congressional leadership, ADAP was well funded federally from fiscal year (FY) 1996—specifically, from a federal level of about \$50 million to in excess of \$500 million by FY 2000. State level contributions to ADAP—particularly in larger, high-AIDS incidence states with active local AIDS advocacy movements—often did very well in stepping up to the challenge with millions of additional dollars of state funds.

Then came “9/11,” changes in Congressional party leadership and a new White House administration, the “dot.com” bubble-burst and economic recessions, and budget constraints at state and federal levels. ADAP, being a program funded at the discretion of political leaders at all levels, came on hard times. Money became even tighter when the Afghanistan and Iraq federal budget costs appeared, and this coming just as patients with HIV/AIDS became noticeable as “higher cost patients” in many privately funded health insurance plans. Attention was focused on the overall drug costs for all health conditions and states began to think of pushing many “optional” health-care services, including HIV/AIDS treatments, off of their publicly funded Medicaid programs. Subsequently, there was steady pressure by private

and public sources with various political perspectives to push patients away from access to healthcare. These patients now had to look to ADAPs for medication coverage.

Meanwhile, the current ADAP pool of more than 90,000 clients remains relatively stable. More effective drugs and treatment have dramatically reduced HIV/AIDS deaths. Although some ADAP clients have returned to work, health insurance, if obtainable, often does not cover their HIV/AIDS drugs. Thousands of new HIV cases among the medically indigent continue to be discovered in expanded outreach and testing programs. Inflating healthcare costs continue to stress the funding stream that now approaches \$1 billion per year in federal, state, and other resource contributions. These trends, with the additional burden of approximately 40,000 new HIV infections each year, strains the fixed amount of money available for ADAP from federal and state sources.

With these built-in pressures on this pool of working, low-income Americans, which may range between 150,000 and 250,000 people (since many are unaware of their HIV status and are not in the healthcare system), ADAPs try vainly to keep up with the resulting stresses and to provide more patients with treatment access. A natural and expected \$100 to \$150 million per year funding demand increase comes just from “normal” program data of the last 5 years—largely driven by longer survival and increased

attempts to enroll in ADAP, within the context of a political climate very determined to allocate resources elsewhere or even not at all because of budgetary, fiscal, or even ideological reasons.

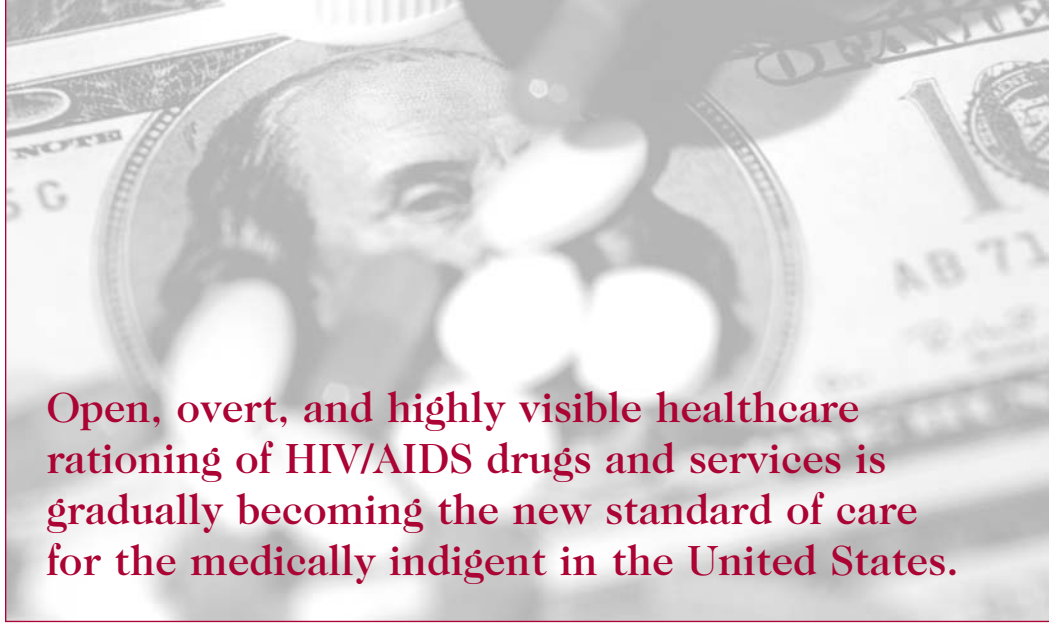
In FY 2000 the demand for ADAP services and the supply of available funding started to separate. Since then, funding has been inadequate, and ADAPs everywhere have suffered the consequences. The pharmaceutical industry responded with substantive discounts to reduce ADAP costs, which helped significantly in allowing fixed public funds to serve more patients. State ADAPs made major efforts to streamline their programs. They cut their already low administrative costs and changed drug delivery systems. Nevertheless, the remaining fiscal pressures have required many states to remove some FDA-approved drugs from their formularies and raised the eligibility standards to exclude greater numbers of HIV-positive people. When these efforts were inadequate to meet the needs of the growing ADAP-dependent population, ADAP waiting lists began to appear in state after state. Open, overt, and highly visible healthcare rationing of HIV/AIDS drugs and services is gradually becoming the new standard of care for the medically indigent in the United States.

Although many of the current HIV/AIDS drugs are still costly even with steep industry discounts, they are still cost-effective. These drugs

prevent progression of HIV disease to life-threatening complications that often require even more expensive care in emergency rooms, hospitals, and nursing homes. Failure to treat the medically indigent on ADAP waiting lists ensures a steady stream of patients entering into the most expensive healthcare settings without the resources to pay for that care.

The result of the increased demand for drugs and services for the increasing numbers of medically indigent with HIV and the spiraling cost of medical care since FY 2002 has been consistent federal under-funding of ADAP. In FY 2004 it appears likely that, despite a widely accepted figure of an additional \$214 million of federal ADAP funding needed, only \$38 million will be provided. Although AIDS and ADAP “champions” exist within the White House and the Democratic and Republican congressional leadership, the budget-hawks have prevailed to date and the fallout descends on ADAPs and those who must look to them for treatment.

Since 1995, the Data Committee of the ADAP Working Group, an advocacy coalition of HIV healthcare providers, AIDS organizations, and research-based drug companies, provides an annual estimate of the ADAP “need number.” This number is based on special ADAP survey data collected as part of the Kaiser Family Foundation–funded annual ADAP Monitoring Project. The Group’s projections have proven accurate for many years and have been widely accepted by Congress and past and present Administrations. Despite having an accurate, known, “need-number,” the AIDS advocacy communities are now in the fourth year of a Congress and an Administration unwilling to fund it. In Congress, the primary obstacles to ADAP funding



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are arguments on the amount of the overall budget that loosely translates as “we don’t have the money.” This is a political answer requiring a political response and political engagement. Finding money for appropriate and necessary activities and uses, such as ADAP, is a political decision in America. It is totally dependant on political leadership and thus calls out for AIDS advocacy. Through grassroots advocacy, democracies educate and reward their elected leaders for good leadership and for making sure that the grassroots problems are addressed and fixed.

Drug access for the medically indigent with HIV/AIDS is now a political challenge. A moral resolution of this challenge can only be effected by the creation of a politically powerful local grassroots advocacy movement since the adverse impacts of HIV/AIDS healthcare rationing—the unnecessary cost burdens, and the damage to patients, families, healthcare budgets and communities—are all local challenges. If these costs and other adverse impacts of such rationing must be borne locally, then the communities affected must demand relief from higher levels of government.

It is time to hit the streets again, to work on election campaigns, to write

your local newspapers, to write your government leaders, to picket at public events, to march on political leaders, to take up civil disobedience, to work with others whose needs in healthcare match ours, to make thousands of insistent phone calls to everyone who is supposed to be leading us. We should not have to do this, but now it is political, and now, for the AIDS advocacy community, it is personal. The question is: Can we get the number of advocacy players onto the national stage that we need in enough numbers, places, and situations across the country to get the ADAP crisis solved? We have done this before. It worked then, and it will work now. Five hundred thousand Americans have died from AIDS. Why should even one more have to die because of a lack of access to available HIV drugs?

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