

The Crisis in America's AIDS Drug Assistance Program (ADAP)

Introduction

The Centers for Disease Control and Prevention (CDC) estimates that between 1,039,000 and 1,185,000 people in the United States were living with HIV in December 2003. In 2002, the CDC's previous estimate showed that between 850,000 and 950,000 individuals were infected with the virus. This increase in estimates reveals the role medicines have played in lengthening the lives of HIV positive people (CDC, 2005).

Yet roughly one-half million people—500,000 individuals—with HIV are going without regular medical care in the United States. Many of them meet the profile and eligibility requirements for participation in ADAP; however, depending on where they live, their chances of actually enrolling in the program are slim to none. For example, in Alabama, Iowa, and Kentucky, 800 people wait for life-saving medications. In Utah and Missouri, the state has already reduced the drug formulary (the list of medications approved for use in the program). In New Hampshire, medical-eligibility restrictions have been placed on the program.

Background

ADAP has cut services to its existing participants—partly because drug prices have risen more sharply than the program's funding, and partly because the medications provided through ADAP have been so effective. With participants now leading longer lives, they spend more time in the program.

In addition, ADAP is a state- and territory-managed program. As a result each U.S. state and territory runs its own ADAP, and there are significant variations in their ADAP eligibility requirements and *drug formularies*. Thus, ADAP participants are not assured of continuous access to treatment when they relocate from one state/territory to another. This is troubling since treatment disruptions can cause the virus to become resistant to the medication in use, as well as to the other medications in its class of drugs.

How the ADAP Crisis can be solved

In March 2005, AIDS Action released a proposal, *Streamlining and Modernizing the AIDS Drug Assistance Program (ADAP) of the Ryan White CARE Act*. The recommendations outlined below are drawn from that proposal, which details the recommendations more fully. If the President and Congress implement AIDS Action's recommendations in the 2005 reauthorization of the Ryan White CARE Act, they will put an end to the ADAP crisis.

AIDS Action's recommendations fall into the following key categories:

Drug Formulary and Price Recommendations

AIDS Action recommends the creation of a baseline drug formulary. However, since non-formulary medications may be difficult to access for HIV positive individuals, AIDS Action proposes, beyond the baseline recommendation, the creation of an "open formulary" in which all drugs available to treat HIV and related illnesses would be included. If an open formulary is not possible, AIDS Action recommends that the baseline formulary include:

- All HIV anti-retroviral drugs;
- All drugs used to prevent the onset of opportunistic infections;
- Specific drugs used to directly treat opportunistic infections; and
- Specific drugs for the treatment of substance abuse; mental health disorders; and nausea associated with HIV drugs.

To ensure that ADAP remains an affordable program for state and federal agencies, AIDS Action recommends that a mechanism be created to purchase drugs at the Federal Ceiling Price—the lowest cost available to federal agencies.

Eligibility Recommendations

AIDS Action recommends that a set of minimum standards be created for all states and territories. More specifically, AIDS Action recommends that all states and territories set eligibility for participation in their respective ADAPs 350% above the Federal Poverty Level (FPL)—or approximately \$31,000 for a single person. Under AIDS Action's plan, states could opt to set the eligibility requirement at a higher percentage than 350 percent of the Federal Poverty Level. In fact, AIDS Action encourages states to set a higher percentage, and the proposal outlines mechanisms to do so.

Funding Recommendation

In FY 2005, ADAP received an appropriation of \$784 million. AIDS Action recommends that the ADAP program be funded at \$1.5 billion in Fiscal Year (FY) 2006, with an increase of \$100 million each year thereafter until FY 2011. The recommendations explicitly state that this funding must not come at the expense of other titles or programs in the CARE Act. For the programs of care and treatment in the other titles are necessary to ensure the continuing success of ADAP.

Congressional Oversight Recommendations

AIDS Action makes further recommendations to help ensure that Congress is better able to oversee ADAP and to understand the beneficial effect of ADAP on health outcomes, including prolonged life and better overall health. More specifically, AIDS Action recommends that the ADAP program be moved from Title II (funding for state and territory programs) into a separate Title V. However, each state and territory should continue to manage its individual ADAP. By placing ADAP into a separate title, Congress will be able to focus more directly on ADAP and the distribution of medications. Such a focus will highlight the need for Congress to continue funding treatment and care at the state level. Additionally, AIDS Action recommends ensuring that health outcome information—including CD4 and viral load levels—is gathered for every individual accessing ADAP. Over time, these levels can be used to track patients' health to ensure that the practices which produce the best health outcomes are employed by HIV care and treatment providers.

Portability Recommendation

AIDS Action recommends that Congress create “portability” of ADAP benefits across states and territories. Currently, ADAP benefits vary from jurisdiction to jurisdiction. Portability would allow individuals who receive drugs through an ADAP in one state to move to another state and be assured of having access to the same HIV medications through the new jurisdiction's ADAP. Thus treatment disruptions would be prevented.

Streamlining and Modernizing the AIDS Drug Assistance Program can be found at http://www.aidsaction.org/legislation/pdf/adap_proposal.pdf.

What is the AIDS Drug Assistance Program (ADAP)?

As a part of Title II in the Ryan White CARE Act, ADAP provides medications for the treatment of HIV disease and it funds the purchase of health insurance for eligible clients. Since the Ryan White CARE Act's reauthorization in 2000, ADAP funds have also been used to pay for services that enhance access and adherence to drug treatments and the monitoring of medications. Currently, ADAP serves 125,000 individuals throughout the United States.

How is ADAP Funded?

As part of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, a discretionary program, ADAP is funded annually through the appropriations process. Congress “earmarks” funds specifically for ADAP spending. Congress then uses a formula, based on AIDS prevalence, to determine ADAP awards for each state and territory. Three percent of the total earmark is, however, reserved for supplemental grants, which are competitive (i.e., states and territories must apply for funding and can be denied).