

John West—standing in front of the AIDS quilt—was so ill in 1996 that he began planning for his death. Powerful antiretroviral drugs, however, gave West new life, and as his health improved, he began teaching and working on a master’s degree.



Program Origins

PART B Eligible Metropolitan Areas/ Transitional Grant Areas

The first HRSA-funded AIDS Service Demonstration Grants, in 1986, brought care to four urban centers. By 1991, when Title I (now Part A) programs began, the number of cities receiving funds had increased fourfold, to 16.

● Part B: Building a Response in Every State

“I think this bill is a fitting tribute to Ryan White, although it is not nearly what he deserves. But it is one of the finest pieces of legislation to come out of this body,” said Orrin Hatch (R-UT) during the final speeches of the Senate floor debate on the original Ryan White Comprehensive AIDS Resources Emergency (CARE) Act legislation.¹ Hatch, a vocal and steadfast supporter of the legislation, made the inclusion of a funding stream to provide services in all States and Territories a top priority in crafting and passing the bill.²

Although much of the attention at the time was on the crisis in the hardest-hit urban centers, Hatch wanted to ensure that funds were available to address HIV/AIDS nationwide. As the ranking Republican member of the Senate Committee on Labor and Human Resources, his support was key to moving the bill forward.

Grants to the States were included in the original version of the Senate bill, and the language made specific reference to “individuals and families with HIV disease in urban and rural areas,” highlighting the desire to serve those outside urban epicenters—a theme that would grow in subsequent years. State grants were not included in the initial House version, but they were ultimately included as Title II (now Part B) in the final version of the bill that passed into law. Over the course of the Ryan White Program, Part B grew into the single largest component of the act, primarily as a result of significant increases in funds to support access to drug therapies.

Collaboration Affects the Scope and Reach of Services

As established, Title II provided States with a variety of mechanisms to provide HIV care and support to their residents, including grants for home- and community-based services, health insurance continuation, and care consortia to provide a wide range of medical and support services. The Title II consortia—associations of public and nonprofit providers working together to assess needs and deliver services—were very much like the service demonstration grants that HRSA had funded in metropolitan areas in the late 1980s and that also provided much of the basis for the structure of Title I.³



Above: a young client looks on as her caregiver checks her antiretroviral medications. ADAP assistance has improved access to antiretrovirals for people, like this teen, who are living with HIV/AIDS. In fact, increases in ADAP funding constitute the most dramatic change to Title II/Part B since legislation was first passed in 1991.

“The main thing is that people were empowered by their government to advocate for their health,” says Christopher Bates, who led the DC Care Consortium in Washington, DC. “People who had HIV, advocates, providers, and government sat around the table and planned. They became a part of the process to conduct needs assessments, determine priorities, and allocate dollars into categories based on collective input.”⁴

Discussing the impact of the new funding stream in the state of New York, Humberto Cruz of the New York State AIDS Institute says, “Ryan White became an element in the overall strategy to address the epidemic. By 1991, New York had built a system of HIV care and support services financed by Medicaid and State and Federal grant dollars. A critical aspect of Ryan White funding was that it provided enhanced resources to maximize our response.”⁵



The original Ryan White CARE Act made reference to “individuals and families with HIV disease in urban and rural areas.” The commitment to reach all parts of the country has helped hundreds of providers, like the Hattiesburg, MS, Family Health Center, offer quality care in a rural setting.

AIDS Drug Reimbursement Program

At its inception, the Title II program also integrated the existing AIDS Drug Reimbursement Program and provided treatments through what became known as the AIDS Drug Assistance Program (ADAP). The Drug Reimbursement Program was launched in 1987 shortly after the Food and Drug Administration’s approval of AZT (zidovudine), when Congress appropriated funds to provide access to this breakthrough medication for people without private insurance or eligibility for Medicaid, Medicare, or State programs. Initially, only AZT was covered, but the list of covered drugs grew to nearly 30 in some States when the program was integrated into the Ryan White Program.⁶

Part B Launches With Speed and Flexibility

Noting the desire to get people into treatment and to serve as many people as possible, HRSA’s Sheila McCarthy recalls the swiftness with which the program was launched in 1987 and the flexibility program managers had to reallocate unspent funds quickly. “When HRSA sent letters to notify States about the program, the returned letter with a signature at the bottom of the page constituted a proposal for funding. Once the program started, we kept a running tab of unspent dollars, and any extra funds would be moved to other States with just a phone call.”³

In later reauthorizations, Title II evolved, continuing to offer service delivery while increasingly focusing on AIDS therapies. One resource-related issue that surfaced early was the concern that States without Title I jurisdictions (i.e., Eligible Metropolitan Areas [EMAs]) were receiving fewer funds to care for their cases than those that had EMAs. The 1996 reauthorization included a provision that favored States without Title I jurisdictions in the allocation of Title II funds, a provision that was further strengthened in the 2006 reauthorization and reinforced in the 2009 reauthorization. These changes were accompanied by a “hold harmless” provision to prevent dramatic shifts in funding from year to year.

TYPES OF PART B GRANTEES

Base and Supplemental

Funds are distributed by formula to States and Territories according to their share of living HIV and AIDS cases. Funding is also weighted to reflect the presence or absence of Part A grantees in the State. Part B supplemental grants are available for States with demonstrated severe need that prevents them from providing medications consistent with Public Health Service guidelines.

ADAP and ADAP Supplemental

Funds are earmarked by Congress for State AIDS Drug Assistance Programs (ADAPs) to provide medications to people living with HIV/AIDS. ADAP supplemental grants are available to States with severe need (5 percent of the earmark is reserved).

Emerging Communities

A portion of Part B base grants funds set-asides for emerging communities, which are metropolitan areas that do not yet qualify as Part A grantees but have between 500 and 999 cumulative reported AIDS cases over the most recent 5 years. All funding is distributed via formula.



“The prohibitive costs meant that something had to happen, or folks were not going to get the medications.”

—Anne Donnelly, *Project Inform*

The 1996 reauthorization also included extensive language related to counseling and voluntary testing of pregnant women, following on the heels of research on the efficacy of AZT in preventing mother-to-child transmission. Another key change was the inclusion of the emerging communities program in 2000 to provide supplemental grants to States with metropolitan areas with between 500 and 1,999 reported AIDS cases in the most recent 5 years. The program was modified to support cities with 500 to 999 cases in the 2006 reauthorization, reflecting the expansion of the criteria for Part A/Title I jurisdictions. The 2009 reauthorization kept this component in tact.

Meeting the Costs Head On

The most dramatic change to Title II was the expansion of ADAP beginning in 1996 in response to the availability of combination therapy (known as highly active antiretroviral therapy or HAART). Although the new drugs were hailed as a medical breakthrough, they were enormously expensive, particularly for underserved populations such as those served by the Ryan White CARE Act.

“Many of us in the community had been working on research funding for so many years, and once treatments were working, we recognized that the prohibitive costs meant that something had to happen, or folks were not going to get these medications,” says Anne Donnelly of Project Inform about the early community efforts to build support for increased ADAP funding. “The State AIDS directors had the same realization at the same time, and we worked in partnership for increased resources.”⁷

RECENT ADAP STATISTICS

- Approximately 175,194 people were served through ADAP in calendar year 2008.
- Most ADAP clients were male (78 percent) persons of color (63 percent), and between the ages of 25 to 64 (94 percent).

ADAP Comes of Age

Efforts to expand access to antiretroviral medications continued unabated, and in 1996, for the first time, ADAP was funded as a specific line item within the Title II appropriation. In the ensuing 14 years, funding for the ADAP program grew from \$52 million to \$835 million (see chart).

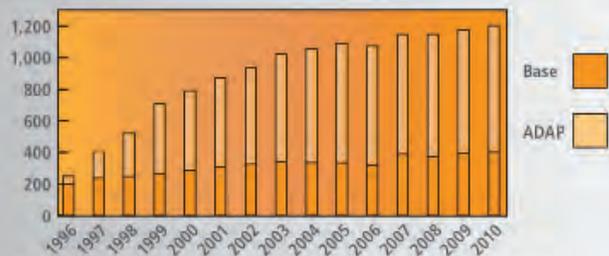
Yet implementing ADAPs at the State level presented many challenges, particularly in the early years. Beth Scalco, Director of HIV/AIDS Program, Louisiana Office of Public Health, arrived in her position in 1996 as Louisiana was receiving its first ADAP award. “There was very little guidance [on setting up a distribution mechanism],” she remembers, “so each State had to figure it out on their own.”⁸ Louisiana first used a State pharmacy to distribute drugs but ran into numerous shipping delays and logistical

BASE AND ADAP FUNDING TITLE II (PART B) 1996–2010

BASE and ADAP FUNDING

Title II (Part B) 1996–2010

In millions of \$



Year	Base	ADAP
1996	\$20,884,027	\$ 52,000,004
1997	\$249,954,016	\$167,000,016
1998	\$257,500,016	\$28,550,0032
1999	\$276,765,024	\$461,000,032
2000	\$295,838,048	\$528,000,032
2001	\$321,969,024	\$589,000,064
2002	\$338,240,032	\$639,000,064
2003	\$352,614,048	\$714,326,080

Year	Base	ADAP
2004	\$350,800,032	\$748,872,064
2005	\$348,338,016	\$787,521,088
2006	\$330,972,032	\$789,546,048
2007	\$405,954,016	\$789,546,048
2008	\$386,748,032	\$808,500,032
2009	\$408,791,000	\$815,000,000
2010	\$418,800,000	\$835,000,000

challenges. After determining the need for a better, more efficient distribution mechanism, the program turned to Louisiana’s 10 State-run public hospitals, which all have an ambulatory HIV clinic and were collectively treating 75 percent of people living with HIV/AIDS in the State.

Challenges to ADAP Access Persist

Even with steadily increasing resources, State ADAPs have faced challenges providing access to drugs for all who need them. Over the years, some States have been forced to implement waiting lists, limit the drugs available, or raise eligibility criteria to save money. Stakeholders at all levels have worked to find solutions to these challenges.

The National Alliance of State and Territorial AIDS Directors ADAP Crisis Task Force, formed in 2003, played an important role in negotiating lower drug prices for ADAPs, resulting in an estimated \$425 million in savings since its formation.⁹ In 2004, the President’s ADAP Initiative allocated \$20 million in one-time funding from outside the ADAP system to reduce waiting lists in 10 states.⁸ Because ADAPs operate as Federal–State partnerships and contributions from the States vary, community advocates have also worked at the State level to increase funding

commitments in States with waiting lists and other limits on access. “Much of the success came when advocates carried the simple message that people should not be on a waiting list for a life-saving treatment,” says Project Inform’s Ryan Clary.¹⁰

The 2006 reauthorization for the first time included a minimum drug formulary for State ADAPs along with a new formula for determining ADAP awards that includes both HIV and AIDS living cases. As in Part A and Part C, the new law also requires States to spend 75 percent of Part B funds on core medical services and created a new supplemental awards program in Part B.

In 2008, HAB distributed medications to more than 175,000 patients through ADAP, continuing its commitment to extending life-saving medications to the underserved. General economic decline in the context of shrinking State budgets, however, continued to place strain on the program. To address this, in 2010 an additional \$25 million was reallocated for ADAP to States with waiting lists or who have implemented strategies to contain costs and delay or prevent a waiting list.

[See Part B funding information by State.](#)

[Read more about Part B.](#)



Above: In 2001, demonstrators gathered in front of the U.S. Capitol after marching to mark the 20th year of the HIV/AIDS epidemic. Commenting on the impact of these and other efforts to broaden access to HIV/AIDS drugs, Project Inform’s Ryan Clary notes, “Much of the success came when advocates carried the simple message that people should not be on a waiting list for a life-saving treatment.”

Credits and Sources

Sources

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Photography

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