

The Basics

The Ryan White CARE Act

In the early 1980s, the United States was confronted by an epidemic of the human immunodeficiency virus (HIV). This virus, left untreated, progresses to a disease called the acquired immunodeficiency syndrome (AIDS) that severely hampers the body's ability to ward off illness and infection. As of 2003, between 1,039,000 and 1,185,000 people are estimated to be living with HIV/AIDS in the United States, and one-quarter of them do not know they are infected.

The Centers for Disease Control and Prevention (CDC) believes that 40 to 60 percent of the infected population does not receive regular treatment. Of those that receive treatment, one study estimated that 20 percent were uninsured, 29 percent were covered by Medicaid only, 6 percent were covered by Medicare only, 13 percent were dually eligible for Medicaid and Medicare, and 31 percent had private insurance. Many of those who are uninsured or underinsured turn to the health care "safety net" for free or low-cost treatment. Medicaid and the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act are two key federal funders of the HIV/AIDS safety net. A variety of private providers, free clinics, community health centers, hospital outpatient departments, and local health departments, among others, receive these funds in return for providing treatment to this population.

Congress created the Ryan White CARE Act in 1990 in response to calls for assistance from a number of urban public hospitals that were struggling financially from uncompensated care provided to individuals dying of AIDS. The Act was named for Ryan White, a teenager who contracted HIV through a blood transfusion and died after an eight-year struggle with the disease.

The Ryan White CARE Act is a series of grant programs that fund treatment services for people with HIV/AIDS who are either uninsured or underinsured; it is not a health insurance program like Medicaid or Medicare. Since its creation, the Act has been reauthorized twice, in 1996 and 2000. Its current authorization expires on September 30, 2005. The authorizing committees of jurisdiction are the Senate Committee on Health, Education, Labor, and Pensions and the House Committee on Energy and Commerce.

The Act funds medical and support services for approximately 533,000 individuals and families living with HIV/AIDS each year. In 2002, 46

percent of people who receive these services through Ryan White were African American, 20 percent were Hispanic, and about one-third were women. At least one of every two clients lived below the federal poverty level, about 25 percent were uninsured, less than 10 percent had any private health insurance, and about 28 percent were enrolled in Medicaid. The Health Resources and Services Administration within the Department of Health and Human Services administers the Act through the HIV/AIDS Bureau.

CARE ACT COMPONENTS

The Act is organized into four titles and one part. Each title directs funds to a different type of recipient. For example, Title I is geared to cities, Title II to states, and Titles III and IV to community-based providers. The funding distribution mechanisms vary among the titles. Title I funds formula grants, which are awarded noncompetitively based on statutorily established factors, as well as competitive grants; Title II funds only formula grants, and Titles III and IV fund only competitive grants. Eighty-five percent of Ryan White funds are distributed through Titles I and II of the Act.

Title I (Part A) of the CARE Act

The first title of the Act provides funds to eligible metropolitan areas (EMAs) that have a population of at least 500,000 and more than 2,000 estimated living AIDS cases (ELCs) within the past five years. Half of the funds are distributed through formula grants and the other half through competitive, supplemental grants based on the severity of the EMA's need. An EMA's formula grant is based on its proportion of ELCs compared to all ELCs across all EMAs. In FY 2005, 51 EMAs were funded.

Title I grant funds may be used for outpatient and ambulatory health services, including dental, substance abuse, and mental health services, and support services such as case management, transportation and housing assistance, nutrition services, day care, and respite care. They may also be used for outreach to people who know their HIV status but are not receiving treatment.

Funds are directed to the chief elected official of the public health agency within the EMA that serves the largest number of people with AIDS. That official appoints a local planning council that has broad responsibilities for targeting funds to the local population living with HIV/AIDS.

Title II (Part B) of the CARE Act

Title II funds three types of formula grants: base grants, AIDS Drug Assistance Program (ADAP) grants, and grants to emerging communities.

Base Grants — The Title II base grant is a formula grant that goes to all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and five U.S. Pacific territories. It has two parts; eighty percent of the award is based on a state's proportion of all estimated living AIDS cases, and the other 20 percent comes from the state's proportion of AIDS

National Health Policy Forum
Facilitating dialogue.
Fostering understanding.

2131 K Street NW, Suite 500
Washington DC 20037

202/872-1390
202/862-9837 [fax]
nhpf@gwu.edu [e-mail]
www.nhpf.org [web]

cases within the state but outside its EMAs. For states with less than 90 AIDS cases, the minimum grant is \$200,000; states with over 90 cases receive a minimum of \$500,000 and territories receive at least \$50,000. Most states provide some services directly but also award subgrants of these dollars to public or nonprofit providers.

AIDS Drug Assistance Program — About one-third of all Ryan White funding and the majority of Title II funds—\$788 million in FY 2005—is earmarked by Congress for the AIDS Drug Assistance Program (ADAP). Federal ADAP funds are distributed by a formula based on each state’s proportion of the nation’s living AIDS cases. In addition to the federal grant, some ADAPs receive state general revenue funding, funds from other parts of the CARE Act, or funds from drug rebates negotiated with drug manufacturers.

ADAPs operate in 57 jurisdictions including all 50 states, Puerto Rico, the District of Columbia, the U.S. Virgin Islands, the Marshall Islands, Guam, American Samoa, and the Northern Mariana Islands. They primarily provide prescription drugs approved by the Food and Drug Administration to eligible individuals, but they may also use funds to pay to continue an eligible individual’s private health insurance, if it has prescription drug coverage, or to fund treatment adherence programs for clients.

States must ensure that an individual has been medically diagnosed with HIV and that he or she qualifies as “low income,” as defined by the state, to receive services from an ADAP. The statute gives states flexibility in

TABLE 1
Ryan White CARE Act Federal Appropriations by Title, Fiscal Years 2001–2006

Fiscal Year	millions \$							Total (billions \$)
	Title I	Title II (includes ADAP)	ADAP	Title III	Title IV	AETC	Dental	
2001	604	911	589	186	65	32	10	1.81
2002	619	977	639	194	71	35	13	1.91
2003	627	1,067	714	201	75	36	13	2.02
2004	623	1,100	749*	200	74	35	13	2.04
2005	618	1,136	788	198	73	35	13	2.07
2006**	\$618	\$1,146	\$798	\$198	\$73	\$35	\$13	\$2.08

* This does not include an additional \$20 million that was appropriated in FY 2004 for emergency funding for ADAPs.

** President’s budget request.

Source: HRSA, “Appropriations History FY 1991 to FY 2005,” table, January 4, 2005, available at <ftp://ftp.hrsa.gov/hab/fundinghis04.xls>, and HRSA, Fiscal Year 2006: Justification of Estimates for Appropriations Committees, available at www.hhs.gov/budget/06budget/documents/HRSABudget06.pdf.

designing their program including setting income and medical eligibility criteria and developing formularies.

The 2000 reauthorization added a supplemental ADAP grant program to help states expand access to treatment specifically for their HIV/AIDS population with income below 200 percent of the federal poverty level. States may only use these funds to purchase drugs, and they must match one dollar for every four federal dollars.

Emerging Communities Grants — In an attempt to respond to the growing epidemic in small urban centers, suburban, and rural areas, Congress added the emerging communities formula grant program to Title II in the 2000 reauthorization. Funds are distributed to communities with a population of at least 50,000 that have between 500 and 1,999 reported AIDS cases over the last five years. Funding is divided into two tiers, with 50 percent awarded to communities with 1,000 to 1,999 AIDS cases and 50 percent to communities with 500 to 999 AIDS cases. Within each tier, funds are distributed to communities based on their proportion of AIDS cases within the tier.

Title III (Part C) of the CARE Act

Whereas the first two titles of the Act provide funds to metropolitan areas and states, the third title funds community-based organizations through a competitive process. Funds are awarded to public and private, nonprofit, primary care providers such as federally qualified health centers (FQHCs), city and county health departments, hemophilia treatment centers, and outpatient facilities at academic medical centers that serve people living with HIV/AIDS. Ninety-eight percent of Title III funds are used to provide early intervention services for uninsured and underinsured individuals. Early intervention services include counseling, testing, primary care, drug therapy, case management, and mental health services, among others. The remaining 2 percent of funds is awarded for capacity building and planning at these same organizations.

Title IV (Part D) of the CARE Act

Title IV funds are targeted to women, infants, children, and youth with HIV/AIDS. Grants are awarded competitively to public and private nonprofit organizations to provide primary and specialty care; substance abuse and mental health services; support services such as transportation, child care, and housing assistance; care coordination; access to clinical trials and clinical research; and supportive services to family members and others who care for this population. A special focus of Title IV is to identify HIV-positive pregnant women and ensure that they have access to prenatal care to prevent mother-to-child transmission of the virus.

Part E authorizes grants for emergency response employees and establishes notification procedures in case of exposure to infectious diseases; the corresponding funds have never been appropriated to implement this program.

Part F: Provider Training, Dental Reimbursement, and Special Projects

Part F of the Act includes three other competitive grant programs. The AIDS Education and Training Centers Program (AETC) is the clinical training component of the Act and funds a network of 11 regional centers with more than 130 sites that conduct multidisciplinary training and education programs for health care providers who treat patients with HIV/AIDS.

The Ryan White dental program was created to alleviate significant difficulties in access to dental care for people living with HIV/AIDS. The program reimburses dental schools, postdoctoral dental programs, and, since the 2000 reauthorization, dental hygiene programs, for the uncompensated services they provide to people living with HIV/AIDS.

The Special Projects of National Significance Program supports the development and replication of innovative models in HIV/AIDS care and service delivery. Grantee organizations include academic health center clinics, FQHCs, community-based organizations, and state and local health departments, among others.

Prepared by Jessamy Taylor. Please direct questions to jrtaylor@gwu.edu.

For more information about HIV/AIDS and Ryan White, see:

■ Jessamy Taylor, "Caring for 'Ryan White': The Fundamentals of HIV/AIDS Treatment Policy," National Health Policy Forum, Background Paper, August 22, 2005; available at www.nhpf.org/pdfs_bp/BP_RyanWhite_08-22-05.pdf

■ CDC, "HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States, 2003," 15; available at www.cdc.gov/hiv/stats/2003SurveillanceReport.htm

■ HIV/AIDS Bureau, "The AIDS Epidemic and the Ryan White CARE Act. Past Successes + Future Challenges. 2004-2005," Health Resources and Services Administration; available at <http://hab.hrsa.gov/publications/progress05>

■ Kaiser Family Foundation, "HIV/AIDS," available at www.kff.org/hiv/aids/index.cfm



The National Health Policy Forum is a nonpartisan research and public policy organization at The George Washington University. All of its publications since 1998 are available online at www.nhpf.org.