

THE RYAN WHITE CARE ACT

Originally enacted in 1990 and reauthorized in 1996 and 2000, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act represents the Federal Government's largest financial commitment to HIV-related health and support services. The Ryan White CARE Act provides funding to states and other public and private organizations to develop, organize, coordinate and operate systems to deliver health care and supportive services to families infected and affected by HIV. The CARE Act is a unique partnership between federal, local and state government; non-profit community organizations, health care and supportive service providers; and people living with and affected by HIV/AIDS, working together to meet the care challenges posed by AIDS. CARE Act funds are used to provide medical care, AIDS drugs, viral load testing, treatment information, adherence support, case management, and other essential support services for tens of thousands of individuals living with HIV/AIDS.

The Need for the Ryan White CARE Act

Each year, as the number of people living with HIV/AIDS in the United States grows, the need for HIV care and services increases. There are nearly one million Americans living with HIV. Almost 300,000 people have progressed to AIDS. As the AIDS epidemic continues to spread in rural, urban, and suburban communities across the country the demands placed on an already over-burdened public health system increase. The CARE Act is vital to ensuring that we can continue to meet the needs of people living with HIV/AIDS, particularly access to life saving drug therapies. The CARE Act has successfully: dramatically improved the quality of life for people living with HIV and their families; reduced expensive hospitalizations; and increased access to care for underserved populations, particularly people of color.

The CARE Act consists of 5 components. While each addresses a specific need, they complement each other to provide comprehensive services for people living with AIDS.

Title I provides emergency relief to metropolitan areas that are disproportionately affected by HIV/AIDS. Jurisdictions qualify for Title I funding if they have a population of at least 500,000 people and report a cumulative AIDS caseload of at least 2,000 cases over the 5 years. Eligible metropolitan areas (EMAs) are located in 21 states, Puerto Rico and the District of Columbia. In 1996, Congress modified the eligibility criteria to slow the number of newly qualifying jurisdictions, bringing the total number of EMAs to 51.

Title I funds may be used for outpatient medical care, case management and supportive services that prevent unnecessary hospitalizations. Local planning councils distribute CARE Act monies. These councils assess the area's needs and coordinate the delivery of comprehensive HIV/AIDS health care services.

Title II provides formula grants to state health departments in all 50 states, the District of Columbia, Puerto Rico and the U.S. territories. Each state must have a comprehensive plan for the delivery and organization of HIV services in the state, including the provision of Title II funds to enhance existing services. In the 2000 reauthorization of the CARE Act, additional funds were made available for partner notification programs and prevention of perinatal HIV transmission. Title II funds may be used to operate HIV care consortia, fund state health insurance programs for people living with HIV/AIDS, provide home health care and support services, and to purchase AIDS-related drugs for low-income individuals through the AIDS Drug Assistance Program (ADAP). Additionally, since there are a limited number of jurisdictions that can qualify for Title I funds, Title II funds are also used by states to provide a range of HIV/AIDS services throughout the state that may be provided to selected metropolitan areas under Title I.

In 1996, Congress created a separate funding line in order to appropriate funds directly to the **AIDS Drug Assistance Program (ADAP)**. **These funds are used specifically for the purchase of HIV/AIDS-related drugs.** This was the result of the rapidly changing world of drug therapies for people living with HIV/AIDS. The scientific breakthroughs in expensive combination drug therapies has dramatically increased the cost of providing appropriate care and services to people living with HIV/AIDS. A direct appropriation to ADAP preserves Title II funds while giving states greater flexibility in providing comprehensive care services that are critical to ensuring the success of new therapies. The benefits of these therapies, which require a strict regimen, can be realized only with access to appropriate medical care, monitoring and other social services.

Title III provides competitive grants to existing community-based clinics and public health providers serving traditionally underserved populations. These organizations provide early intervention and ongoing comprehensive HIV/AIDS services. Title III funds can be used for prevention and risk reduction counseling, HIV testing, medical care, and prescription drugs. Title III funds may also be used to address the “co-epidemics” that occur frequently in association with HIV infection, including tuberculosis and substance abuse. In some areas of the country, particularly rural areas, Title III is the only source of medical care and other critical HIV services.

The **Title IV** provides comprehensive, community-based, family centered services to children, youth, and women living with HIV and their families. This is especially critical since women account for almost a quarter of all HIV infections in the United States, nearly triple the number of cases 10 years ago. Title IV program services include primary and specialty medical care, and psychosocial services as well as outreach and prevention to provide a continuum of care for at-risk populations.

Part F provides competitive grants for projects of national significance. Given the complexity of the current HIV treatment regimens, Part F provides critical funds to educate and train health care providers in HIV/AIDS care through the AIDS Education & Training Centers (AETCs). As the training arm of the Ryan White CARE Act, the AETCs ensure that health care providers have access to the most up to date information and training on competent and compassionate HIV/AIDS care. Part F also provides funding for the AIDS Dental Reimbursement Program. The HIV/AIDS Dental Program assists accredited dental schools and post-doctorate dental programs with the costs associated with providing oral health treatment to patients with HIV/AIDS.

Investments for the Ryan White CARE Act

The CARE Act has successfully served as the health care and social service safety net for Americans living with HIV/AIDS. In recent years, the program has received bipartisan support from Congress and the Administration. As the pandemic continues, there are increasing numbers of people living with HIV/AIDS and subsequent growth in the demand for HIV-related services that continuously challenge the CARE Act to meet the needs of people living with HIV.

The advent of promising, expensive new drugs and the associated increase in demand have added to the health care costs that the CARE Act must subsidize. The AIDS Drug Assistance program (ADAP) continues to strive to meet the demand for new and potentially lifesaving and life-extending drug therapies. As a result, additional funds are required specifically for the ADAP program so that it can continue to address the growing demand for prescription drugs for uninsured and under-insured people with HIV/AIDS.

The high cost of these new drug therapies should be viewed within a broader context. **The promise of new HIV therapies made available through ADAP can only be fully realized in the context of providing appropriate and competent medical care and supportive services.** All titles of the CARE Act play a critical role in achieving this goal.

AIDS Action and its members are appreciative of Congress and the current Administration's continued support of the Ryan White CARE Act over the past decade. As a result of the care, treatment, and services provided by the CARE Act, thousands of people living with HIV/AIDS have been able to lead productive lives.

The CARE Act has made an important contribution to the success stories of the AIDS pandemic in the United States:

- People with HIV/AIDS are living longer, more productive lives.
- Local control has enabled communities to design HIV care and treatment services that meet their specific needs.
- A strengthened safety net has improved access to appropriate care, treatment and services for people living with HIV/AIDS.
- An effective model of service delivery has developed that can be adapted to meet the needs of other life-threatening diseases.

As the AIDS pandemic continues, particularly in disenfranchised communities in the U.S., the need for CARE Act services is even more critical. All of the Titles of the Ryan White CARE Act must be adequately funded to ensure that the health care and supportive services infrastructure established through the CARE Act can continue to meet the broader needs of individuals living with HIV/AIDS, specifically the provision of life saving or life-extending treatment. To accomplish this, increased funding for each Title of the CARE Act is critical.

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