

The Ryan White CARE Act: An Update of Reauthorization from 2000 to 2004

Overview

The Ryan White Comprehensive AIDS Relief Emergency (CARE) Act was first enacted in 1990. The CARE Act is required to be reauthorized, a process of reviewing and amending the law, every five years. The next reauthorization is scheduled to take place by September 30, 2005.

The CARE Act is the largest source of federal funding solely devoted to people living with HIV/AIDS and their families. It supports a range of HIV care and medical support services, from HIV testing and counseling to home hospice care. These services are provided through several funding mechanisms, including grants to cities and states, direct grants to health care providers, and targeted funds to support HIV prescription drugs, dental services, and other activities. In 2004, Congress appropriated more than \$2 billion dollars to the U.S. Department of Health and Human Services, Human Resources and Services Administration (HRSA) for distribution to CARE Act programs.

This policy brief provides an overview and update of the four major themes developed in the most recent reauthorization (in 2000) of each Title of the CARE Act and funding developments from the 2000 reauthorization to June 2004.

Themes of the 2000 Reauthorization

Redirecting funds to meet current needs. The reauthorization recommended modifying the formula for allocating funds for Titles I and II to include HIV in addition to AIDS cases. This recommendation to shift formulas reflects the current experience of the HIV epidemic in the U.S., where modern drug therapies may delay and, in some cases, prevent people living with HIV from progressing to an AIDS diagnosis. Therefore, using HIV and AIDS cases in a state or city to determine the

distribution of resources would be a more accurate way of determining where funds should be allocated.

The reauthorization of the Ryan White CARE Act required HRSA and the Centers for Disease Control and Prevention (CDC) to estimate the number of people living with HIV who are not in care. HRSA and CDC sponsored an Institute of Medicine (IOM) study, *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*, which concluded that the numbers of reported HIV cases are not yet accurate or reliable enough to be used in making funding decisions. Consequently, the Secretary of the U.S. Department of Health and Human Services was unable to certify that the current data on HIV are sufficient to allow funding to be allocated on the basis of HIV. The IOM report made recommendations to improve allocation formulas. The Ryan White CARE Act now calls for the shift to occur in 2007.

Bringing HIV positive people into care. The current HIV drug therapies are more effective if treatment is well-timed and aggressive. The 2000 reauthorization focused on reaching out to individuals who know their HIV positive status but are not in care. One strategy is to develop connections among medical entry points that care for newly diagnosed people living with HIV including STD or family planning clinics, homeless shelters, mental health and substance abuse programs, and HIV testing, referral, and outreach sites. Ryan White funds can now be used to combine HIV testing and counseling sites together with grantees providing medical care.

Improving the quality of care delivered with Ryan White funds. All four Titles of Ryan White were required to ensure that high quality health care and related services are provided to HIV positive people through the development of quality management programs. States and cities are permitted to use up to five percent or \$3 million of their Title I and II grants each year on this activity. Grantees must ensure consistency with U.S.

Public Health Service clinical guidelines for the care of people living with HIV.

Coordination between Ryan White and Medicaid and State Children's Health Insurance Program (SCHIP). In order to maximize available CARE Act dollars, the 2000 reauthorization affirmed that people living with HIV who are eligible for Medicaid or SCHIP should use those programs to pay for Medicaid or SCHIP-covered services. States and cities receiving Titles I and II monies were required to establish formal linkages with Medicaid and SCHIP to ensure that Medicaid or SCHIP will pay for allowable services delivered by Medicaid or SCHIP providers to people living with HIV.

Title Overview and Update

Title I. Title I of the Ryan White CARE Act provides grants to 51 Eligible Metropolitan Areas (EMAs) in the United States, including Puerto Rico. Title I funds are distributed through Planning Councils and support the provision of outpatient medical and dental care, prescription drugs, mental health and substance use services, home hospice care, transitional housing, non-emergency transportation, nutritional services, and case management to area residents living with HIV.

Total funding in 2001: \$604.2 million
Total funding in 2004: \$615.0 million

In addition to the formula shift from AIDS case reporting to HIV and AIDS case reporting, major changes to Title I in the Ryan White CARE Act 2000 included the composition of the Planning Councils. The reauthorization language contained a conflict of interest provision requiring 33 percent of the members of each EMA Planning Council to be people living with HIV who receive Title I services and are not aligned as employees or representatives of Title I grantees.

Planning Councils must include social service providers, mental health and substance abuse providers, public health agencies, hospitals and/or health care planning agencies, and historically underserved populations. Planning Councils must ensure that the allocation of resources and the development of a comprehensive plan consider people living with HIV who are not in care; disparities in access to care among sub-populations and historically underserved communities; coordination of services with HIV prevention programs; and substance abuse prevention and treatment. The 2000 reauthorization identified several additional sub-

populations, including HIV prevention providers, housing and homeless service providers, and HIV positive former prisoners, who must have representation on Planning Councils.

The 2000 reauthorization also attempts to change the Title I grant formula, moving over time from distributing funds based on the current ten-year weighted AIDS case count to a ten-year weighted HIV and AIDS case count. However, this change has not occurred because, as noted above, the Secretary of the U.S. Department of Health and Human Services has not certified that the data are sufficient for the formula shift to be implemented due to inconsistent data mechanisms as detailed by the IOM study. The study suggests a mechanism to remedy this issue and, the formula shift is now scheduled to be implemented in 2007.

Title II. Title II of the Ryan White CARE Act provides grants to all 50 States, the District of Columbia and all U.S. territories and are distributed based on a formula that estimates the number of people with AIDS in each state and the estimated number of people living with AIDS outside of the state's EMAs. Title II supports outpatient medical, dental, developmental, and rehabilitative services, home and community based services, continuation of health insurance coverage, prescription drugs, HIV care consortia, and supportive services. Title II also includes the AIDS Drug Assistance Program (ADAP) which supports the provision of HIV medications and related services in all 50 states. Approximately 136,000 HIV positive people who are uninsured or underinsured receive services from ADAP yearly.

Total funding for 2001: \$911 million, of which \$589 million was for ADAP
Total funding for 2004: \$1.086 billion, of which \$748.9 million is for ADAP

The 2000 reauthorization for Title II brought significant changes, including a supplemental program for emerging communities, a perinatal testing requirement, a partner notification program, and the ADAP competitive grant program. The reauthorization made funding available to enhance notification, counseling, and referral services as components of partner notification programs and to support states that implement mandatory testing of newborns whose mothers' HIV status is unknown. As in Title I, the 2000 reauthorization recommended modifying the formula to a ten-year weighted HIV and AIDS case count over time, but the change was not

certified by the Secretary of the Health and Human Services.

The Title II supplemental grant for emerging communities distributes CARE Act funds to cities that do not qualify as Eligible Metropolitan Areas under Title I. Emerging communities are metropolitan areas that are experiencing growing rates of HIV infection but have lower proportions AIDS cases than the EMAs. Supplemental funding is provided to two categories of cities: 1,000-1,999 AIDS cases reported over the last five years and 500-999 AIDS cases reported over the last five years. The emerging communities apply for the Title II supplemental through a grant application to HRSA.

ADAP now includes a competitive grant to increase access to HIV medications in states with a demonstrated need for improved drug access and a significant number of people living at or below 200 percent of the Federal Poverty Level (\$37,700 annually for a family of four in 2004). This grant program is funded by redistributing 3 percent of ADAP funding to states in need, but the grants do not result in reduced ADAP funding for any state.

Title III. Title III of the Ryan White CARE Act provides funds to HRSA to provide competitive grants to support medical treatment and medical support services for people living with HIV, including HIV testing, early intervention, risk reduction counseling, case management, outreach, oral health, nutrition, and mental health services. Title III providers include community and migrant health centers, city or county health departments, Health Care for the Homeless Centers, and community-based organizations that offer primary health care services to more than 150,000 people. Title III planning grants may be used to provide early intervention services and to expand capacity and access to HIV care in rural areas and underserved areas.

Total funding for 2001: \$185.9 million
Total funding for 2004: \$197.2 million

Title IV. Title IV of the Ryan White CARE Act serves women, youth, children, and families through the provision of comprehensive health care services, including primary medical services, case management and related social services, and access to research. Title IV grants are administered in a three-year cycle. In fiscal year 2001, 71 public and nonprofit grants were awarded. Title IV grants provide or arrange direct HIV services at several hundred clinical sites that cumulatively provide 600 support services. Title IV provides services to over

49,000 women, infants, children and youth and has been instrumental in reducing the rates of perinatal HIV transmission in the United States. In some localities, the rate has been reduced to zero.

Total funding for 2001: \$65 million
Total funding for 2004: \$73.1 million

Part F. Part F of the Ryan White CARE Act includes the HIV/AIDS Dental Reimbursement Program, AIDS Education and Training Centers, and Special Projects of National Significance.

The HIV/AIDS Dental Reimbursement Program assists dental education programs in providing oral health care services to people living with HIV. Oral health services are an identified area of significant unmet need for people living with HIV.

Total funding for 2001: \$10 million
Total funding for 2004: \$13.3 million

The AIDS Education and Training Centers (AETCs) are a network of 14 regional centers that educate health care providers about the prevention and treatment of HIV. AETCs provide ongoing provider education and information through an established network of trained providers who are HIV expert resources in their local communities.

Total funding for 2001: \$31.6 million
Total funding for 2004: \$35.3 million

The Special Projects of National Significance (SPNS) program supports innovative HIV service delivery models to provide health and social services to historically underserved populations and communities of color.

Funding: SPNS programs receive 3 percent of the funds appropriated to each of the four Titles of the CARE Act up to \$25 million each year.

Conclusion

The 2000 reauthorization of the Ryan White CARE Act affirmed the need for continued federal assistance in combating the HIV epidemic in the United States. The reauthorization attempted to modernize the CARE Act through the use of HIV surveillance data, quality management programs, alternative sources of funding (Medicaid and SCHIP), and linkages with health and social service providers.

The next reauthorization of the Ryan White CARE Act is due on September 30, 2005. Major issues for the next reauthorization include continuing to modify Title I and II formulas based on AIDS to a formula based on HIV. HIV has emerged as a crisis among individuals in particularized groups and settings such as rural communities and people of differing race and ethnicity. Individuals living with HIV from emerging and newly revealed populations require appropriate and culturally relevant medical care and medical support services. Finally, a quarter million people are unaware that they are HIV positive, and an estimated 42-59 percent of HIV positive individuals who are aware of their diagnosis are not receiving care. Early and continuous treatment contributes to better and less costly treatment outcomes. Connecting people to care and ensuring “standard of care” treatment will be important issues in the upcoming reauthorization. The success of the next reauthorization will be dependent on the cumulative efforts of all those committed to serving individuals living with HIV, their families, and communities.