until it's over
AIDS ACTION
POLICY BRIEF

The Ryan White CARE Act: A Reauthorization Update 2006 - Present

June 2008

Overview

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was first enacted in 1990. The CARE Act is usually "reauthorized" (a process of reviewing and amending the law) by Congress every five years. However, the current version of the CARE Act is scheduled to expire or "sunset" on September 30, 2009 if it is not reauthorized prior to that date. If it is not reauthorized, Congress can also extend the Ryan White CARE Act through various methods including amendments to other bills or a continuing resolution.

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 Fiscal Year 2007, 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 of the changes made to the Ryan White CARE Act by the most recent reauthorization, the "Ryan White HIV/AIDS Treatment Modernization Act of 2006" which was signed into law on December 19, 2007.

Title Overview and Update

Title I. Title I or "Part A" of the Ryan White CARE Act provides grants to 56 jurisdictions that meet certain eligibility standards. The most recent reauthorization divided the jurisdictions into two categories Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs). There are 22 EMAs and 34 TGAs. To be eligible as an EMA, jurisdictions must have a cumulative total of more than 2,000 AIDS cases over the most recent five-year period and a total population of 50,000 or more persons. To be eligible as a TGA, jurisdictions must have a cumulative total of at least 1,000, but not more than 1,999, cumulative AIDS cases during the most recent five years, and a population of 50,000 or more persons.

The reauthorization also changed how Title I funds are distributed. The funds are now distributed based on the number of living HIV/AIDS cases diagnosed in the previous year in a jurisdiction rather than AIDS cases alone. In addition the reauthorization required all States (including EMA and TGA jurisdictions) to switch to a name-based HIV reporting system rather than a code based system. States that had not previously switched to a name based system are allowed to continue reporting HIV cases under their code based system for a transition period through the end of the reauthorization. However those states must accept a reduction of 5% of their total cases as a penalty for not using a name based system.

The reauthorization also requires that 75% of funds support the provision of 13 "core

medical services." Those services are: outpatient and ambulatory health services; AIDS Drug Assistance Program treatments; AIDS pharmaceutical assistance; oral health care; early intervention services; health insurance premium and cost sharing assistance for low-income individuals; home health care; medical nutrition therapy; hospice services; home and community-based health services; mental health services; substance abuse outpatient care and medical case management, including treatment adherence services. The remaining 25% of funds may go for "support services" which are not fully defined but could include services such as case management, transportation, nutritional services and linguistic services as long as they are in support of a medical outcome. Eligible jurisdictions may apply for a waiver from "core medical service" requirements from the Health Resources Services Administration (HRSA). Title I serves up to 200,000 people living with HIV/AIDS each year.

Total Title I funding in 2008: $627.2 million

Title II. Title II or "Part B" of the Ryan White CARE Act provides grants to all 50 States, the District of Columbia and all U.S. territories. Like Title I the new reauthorization requires that funding allocations be distributed based on name-based HIV reporting (see discussion above). Title II is also subject to the "core medical services" rule as discussed above.

The reauthorization changed the distribution of the state formula to focus more funding on rural areas and states which lack Title I jurisdictions. Title II supplemental funds additionally provide grants for "emerging communities" which are cities that do not meet eligibility requirements for Title I but which are experiencing high rates of HIV infections.

Title II also includes the AIDS Drug Assistance Program (ADAP) which supports the provision of FDA approved prescription medications for uninsured or underinsured people living with HIV (including anti-retroviral medications for HIV along with other medications for opportunistic infections and in support of adherence) in all the states, territories and the District of Columbia. ADAP may be used to provide insurance coverage for people living with HIV. Approximately 142,000 HIV-positive people received services from ADAP in 2006. The 2007 reauthorization changed the ADAP supplemental funding process. As of October 2007 this change, along with changes to the Medicare Part D program, resulted in the elimination of all ADAP waiting lists. However, it is not yet clear whether this success can be sustained for the life of the reauthorization.

Total Title II funding for 2008: $1195.3 million of which $400.9 million is for Title II base funding and $794.4 million is for ADAP

Title III. Title III or "Part C" 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. Like Titles I and II, Title III is subject to the "core medical services" provision in the new CARE Act. Otherwise, there were relatively few changes in the program. Title III providers include community and migrant health centers, city or county health departments, Health Care for the Homeless Centers, and community-based organizations. These programs offer primary HIV 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 Title III funding for 2008: $198.8 million

Title IV. Title IV or "Part D" 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. They also offer prenatal care and testing to pregnant women including services to prevent mother to child transmission of HIV. Unlike Titles I, II and III, Title IV grants were not subject to the core medical services requirement. Title IV grants are administered in a three-year cycle. Title IV grants provide or arrange direct HIV services at several hundred clinical sites that cumulatively provide 600 different types of 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 Title IV funding for 2008: $73.7 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 Dental Program funding for 2008: $12.86 million

The *AIDS Education and Training Centers (AETCs)* are a network of 11 regional and 4 national centers that educate health care providers about the prevention and treatment of HIV. Within the CARE Act, the AIDS Education and Training Centers (AETCs) are responsible for building and maintaining a well-educated health professional work-force in the national effort to improve access to quality HIV treatment, care and prevention, reduce disparities, and enhance clinical capacity. While the AETC program has trained more than 1,000,000 HIV/AIDS providers, advances in HIV prevention and treatment continue to increase in scope and complexity. AETC education and training efforts include professionals (from physicians to office managers) serving individuals in the most need for HIV care and prevention living in inner city, suburban, and rural settings. AETCs provide ongoing provider education and information through an established network of trained providers who are HIV expert resources in their local communities.

Total AETC funding for 2008: $34.1 million

The *Special Projects of National Significance (SPNS)* program supports HIV models that allow quick response to emerging needs of individuals receiving assistance under this title and to fund special programs to develop a standard electronic client information data system.

Total SPNS Funding for 2008: $25 million

Minority AIDS Initiative. Congress established the Minority AIDS Initiative (MAI) in FY 1999 as the result of the advocacy by the Congressional Black Caucus to address the growing proportion of HIV/AIDS in the African American and Latino communities. The initiative provides funds through multiple Department of Health and Human Service programs in addition to the Ryan White CARE Act to address the growing impact of the HIV epidemic on all ethnic and racial minorities in the U.S. The Ryan White HIV/AIDS Treatment Modernization Act of 2006 authorized the MAI program officially for the first time. Prior to this reauthorization, the program had existed solely through the appropriations process. In addition the MAI was authorized as a competitive grant program for the first time. In the past funding had been solely distributed on the basis of a formula based on the number of AIDS cases in communities of color. Consequently implementation of the program

has been substantially delayed and grant awards were made in August, 2007. In previous years, MAI grants were distributed with the Ryan White grant cycles.

Total MAI funding for 2008: $402.6 million (across multiple HHS programs)

Additional Changes. In addition to the changes made to the Title system listed above, the Ryan White HIV/AIDS Treatment Modernization Act also made additional changes to the program. It established an Early Diagnosis Grant Program that provides funding for states with state law or regulation that calls for: voluntary opt-out testing of all pregnant women and universal testing of newborns; or voluntary opt-out testing of clients at STD clinics and substance abuse treatment centers. Thirty million dollars in funding would be taken out of the Centers for Disease Control and Prevention (CDC) to finance this program. Most HIV advocacy organizations have opposed this provision as duplicative and wasteful.

The Act also allows the creation of a Severity of Need Index (SONI) which would ultimately be used to replace formula allocations in Title I and II. The SONI is currently being developed by HRSA and may be unveiled in the near future.

Conclusion

The next reauthorization of the Ryan White CARE Act is due on September 30, 2009 unless Congress reauthorizes the Act or extends the by other means before that date. Major issues for the next reauthorization include assessing how well the changes made in the most recent reauthorization have worked. Additionally major changes are being made to federal and private healthcare systems and it remains to be seen how the Ryan White CARE Act will fit into those changes.

HIV has emerged as a crisis among individuals in particular groups and settings such as rural communities, people of differing race and ethnicity and people marginalized by homelessness and poverty. Individuals living with HIV from emerging and newly revealed populations require culturally-appropriate, relevant medical care and medical support services. Finally, it is estimated that 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 status are not receiving medical 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.