

The Ryan White CARE Act 2000 Reauthorization

Overview

As the Ryan White CARE Act enters its second decade, it continues to be a critical source of care and services for people living with HIV/AIDS. The Ryan White Comprehensive AIDS Relief Emergency (CARE) Act was first enacted in 1990. Ryan White is a significant source of federal funding for people living with HIV/AIDS in the United States. The Ryan White CARE requires reauthorization every five years, and on October 20, 2000, the Act was reauthorized. Congress has appropriated \$1.8 billion dollars to be distributed by the U.S. Department of Health and Human Services, Human Resources and Services Administration (HRSA) to Ryan White programs in the next fiscal year. This policy brief provides a brief overview of each Title of the Ryan White CARE Act and describes the major changes enacted in the 2000 reauthorization.

The Ryan White CARE Act provides funding to support a range of HIV care and services, from HIV testing and counseling to home hospice care. These services are provided through a number of different funding mechanisms, including grants to cities and states that distribute the funds through a community planning process, direct grants to health care providers, and targeted monies to support HIV prescription drugs, dental services, and other activities.

The 2000 reauthorization of the Ryan White CARE Act attempts to integrate the diverse needs of people liv-

ing with HIV/AIDS in the U.S. by encouraging providers and community-based organizations to care for them, encouraging people living with HIV to receive health care and prescription drugs, and encouraging Ryan White grantees to provide high quality services to their clients. A number of themes are revisited throughout the reauthorization:

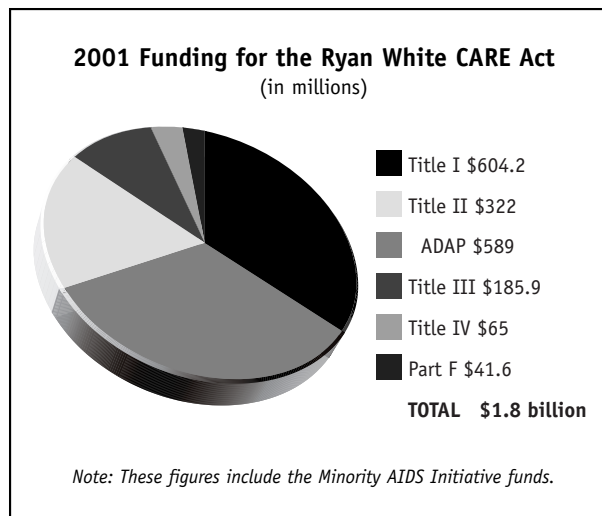
Redirecting funds to meet current needs. Funding for Titles I and II will shift within the next five to seven

years as the formula will be expanded to include HIV, in addition to AIDS, cases. This formula shift reflects the current experience of the AIDS epidemic in the U.S., where modern drug therapies prevent many people living with HIV from progressing to an AIDS diagnosis. Therefore, using the number of HIV and AIDS cases in a state or city to determine the distribution of resources has more meaning in the current environment. States and cities are now faced

with the significant challenge of establishing adequate HIV surveillance systems over time in order to qualify for needed funds.

Bringing HIV positive people into care. The current HIV drug therapies are more effective if treatment is well-timed and aggressive. Ryan White reauthorization focuses on reaching out to individuals who know their HIV positive status but are not in care. One strategy for doing this is to develop linkages between medical entry points that may care for newly diagnosed people living with HIV such as hospitals, STD or family plan-

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ning clinics, prisons/jails, homeless shelters, mental health and substance abuse programs, and HIV testing, referral, and outreach sites. For example, Ryan White funds can now be used to co-locate HIV testing and counseling sites with Ryan White grantees providing medical care.

The reauthorization of the Ryan White CARE Act requires HRSA and the Centers for Disease Control and Prevention to estimate the number of people living with HIV who are not in care. The states and cities receiving Titles I and II monies will be responsible for targeting funding to reach HIV positive communities and bring them into care.

Improving the quality of care delivered with Ryan White funds. All four Titles of Ryan White have new requirements intended to ensure that high quality health care and related services are provided to people living with HIV/AIDS through the development of quality management programs. States and cities are permitted to use up to 5% or \$3 million of their Title I and II grants each year on this activity. One means of ensuring that standards of quality HIV care are followed in Ryan White funded programs is the new provision found in all four Titles requiring that grantees ensure consistency with U.S. Public Health Service clinical guidelines for the care of people living with HIV/AIDS.

Coordination between Ryan White and Medicaid and State Children's Health Insurance Program (SCHIP).

In order to maximize available Ryan White dollars, the Ryan White CARE Act reauthorization affirms that people living with HIV/AIDS 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 must 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/AIDS.

The reauthorization language indicates that both Titles I and II must consider the availability of Medicaid and SCHIP providers and services in the development of the community planning process. Providers caring for people living with HIV/AIDS who are not currently Medicaid and SCHIP providers may want to explore the availability of capacity grants or other technical assistance from HRSA to assist them in applying for Medicaid provider identification numbers.

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/AIDS.

➔ **Total funding for 2001: \$604.2 million**

There were two major changes to Title I in the Ryan White CARE Act 2000 reauthorization: the composition of the Planning Councils and the formula shift from AIDS cases to HIV and AIDS cases by 2007.

The reauthorization includes a conflict of interest provision that requires that 33% of the members of each EMA's Planning Council are people living with HIV/AIDS receiving Title I services (or their parents or caregivers) who are not aligned (as employees or representatives) of Title I grantees. This requirement will be phased in by 2002.

HRSA is currently developing guidance to assist Ryan White Planning Councils in meeting this provision. Technical assistance may be particularly useful as Planning Councils recruit new members who require orientation and education regarding the community planning process. New York State has a leadership-training program for Planning Council members that other EMAs may want to model to develop similar programs.

In addition to the new requirements for Planning Council membership discussed above, the Ryan White reauthorization seeks to reflect the demographics of the HIV population in the EMA through the identification of specific sub-populations affected by HIV/AIDS who must have representation on the Planning Council. These populations include HIV prevention providers, housing and homeless service providers, and HIV-positive former prisoners who have been released within the last three years or their representatives. Planning Councils continue to include social service providers, mental health and substance abuse providers, public health agencies, hospitals and/or health care planning agencies, and historically underserved populations.

The Planning Council is also directed to ensure that the following specific populations and service coordination issues are considered in its allocation of resources and the development of a comprehensive plan: people living with HIV who are not in care, dis-

parities in access to care among sub-populations and historically underserved communities, coordination of services with HIV prevention programs, and substance abuse prevention and treatment. Planning council meetings must be open and all documents must be available to the public.

The formula shift for Title I grants will modify the distribution of funds from the current 10-year weighted AIDS case count to a 10-year weighted HIV and AIDS case count over time. This change is expected to occur by 2005, if the Secretary of the U.S. Department of Health and Human Services (Secretary) certifies that the data is sufficient and the formula shift can be implemented. The formula shift will be employed at the latest by 2007.

The Institute of Medicine (IOM) has been directed to conduct a study in the states and localities to determine if the HIV surveillance data that currently exists is accurate and appropriate for including in the formula for the distribution of Ryan White monies. The Secretary is authorized to provide data collection grant funds to EMAs and states for technical assistance on collecting HIV data.

Title II

Title II of the Ryan White CARE Act provides grants to all 50 States, including the District of Columbia and U.S. territories. Title II funds 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 includes the AIDS Drug

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Assistance Program (ADAP), which supports the provision of HIV medications and related services in all 50 states. An estimated 125,800 people living with HIV who are uninsured or underinsured received services from ADAP in 2000.

➔ **Total funding for 2001:** \$911 million, of which \$589 million is for ADAP

The most significant changes in the Ryan White reauthorization for Title II involve the new supplemental program for emerging communities, the perinatal testing requirement, the partner notification program, the ADAP competitive grant program, and the formula shift.

The Title II supplemental for emerging communities will distribute Ryan White funds to cities that do not qualify as Eligible Metropolitan Areas under Title I. These are metropolitan areas with lower proportions of HIV/AIDS cases than the EMAs that are experiencing growing rates of HIV infection. In order to be eligible, a metropolitan statistical area must have a population base of 500,000. Supplemental funding will be provided to each of the two categories of cities: those with 1,000-1,999 AIDS cases reported over the last five years, and those with 500-999 AIDS cases reported over the same period of time. The emerging communities will apply for the Title II supplemental through a grant application to HRSA. States are not required to provide matching funds to receive these monies.

The Title II supplemental received sufficient funding in FY2001 appropriations to begin implementation. It is expected that the first tier cities (1,000-1,999 AIDS cases) will receive approximately \$1 million each and that the second tier (500-599 AIDS cases) cities will receive approximately \$250,000 each. While the funding may be somewhat variable depending on the appropriations process, the U.S. Department of Health

and Human Services is required to make \$10 million available each year. However, eligibility for the supplemental is not fixed and cities could gain or lose funding annually.

Thirty million dollars has been made available to enhance notification, counseling, and referral services as components of partner notification programs. Preference will be given to states with HIV reporting systems that are sufficiently accurate and reliable. Bonuses will be available to states that adopt partner notification programs consistent with Centers for Disease Control and Prevention guidelines. Individuals living with HIV/AIDS will not be penalized for non-cooperation with the program (identification of partners, etc.).

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An additional \$30 million will be made available to support states that implement mandatory testing of newborns for whom the mother's HIV status is unknown. Grants will also be distributed to a limited number of states that reduce perinatal transmission through other means. States demonstrating the most significant reductions in the rates of new perinatal HIV transmission or reductions in the incidence of HIV/AIDS among women of childbearing age will be eligible for funding.

The IOM will study barriers to the testing of newborns and make recommendations on a state-by-state basis to reduce the incidence of perinatal HIV transmission. States must respond to the IOM recommendations in a report to the Secretary by 2004.

ADAP will now include 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% of the Federal Poverty Level (\$17,050 annually for a family of four in 2000). The criteria for this grant will be developed by the Secretary, but is likely to include an

assessment of the state's eligibility standards and ADAP formulary composition. This grant program will be funded by redistributing 3% of the ADAP funding to specific states in need of restructuring their ADAP programs, but the grants will not result in reduced ADAP funding for any state. Eligibility for this grant program requires a state match of one state dollar to every four ADAP grant dollars.

The formula shift for Title II grants is the same concept described above for Title I. The shift will modify the disbursement of funds from the current 10-year weighted AIDS case count to a 10-year weighted HIV and AIDS case count over time. This change is expected to occur by 2005 or 2007. The IOM study applies to both Titles I and II.

Title III

Title III of the Ryan White CARE Act provides competitive grants to support medical and support services for people living with HIV/AIDS, including HIV testing, early intervention, risk reduction counseling, case management, outreach, oral health, nutrition, and mental health services. There are 181 Title III providers in 40 states, the District of Columbia, and Puerto Rico. These Title III providers include community and migrant health centers, city or county health departments, Health Care for the Homeless Centers, and community-based organizations. In 1997, 96,000 people received primary health care through Title III providers. These facilities provide a primary point of access to comprehensive health care for low-income, medically underserved populations.

➔ **Total funding for 2001:** \$185.9 million

There were a few modifications to Title III in the Ryan White reauthorization involving planning grants and administrative costs. Title III planning grants can now be used to provide early intervention services as

well as to expand capacity and access to HIV care in rural areas and underserved areas. These grants will be distributed in increments of no more than \$150,000 for three years. The reauthorization also increased the allowable percentage of grants that can be spent on administrative costs from 7.5% to 10%.

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. In 1998, 48 public and nonprofit grantees were funded in 27 states, D.C., and Puerto Rico to provide and/or arrange direct HIV services at over 300 clinical sites. In 1997, Title IV provided services to over 16,000 people living with HIV/AIDS. Title IV has been instrumental in reducing the rates of perinatal HIV transmission in the United States.

➔ **Total funding for 2001:** \$65 million

The two significant reauthorization changes in Title IV pertain to HIV clinical trials and administrative costs. Title IV grantees are no longer required to ensure that a significant number of women and children will be participating in HIV research. Grantees are now required only to provide enhanced information and education on HIV clinical trials while the National Institutes on Health studies methods of improving voluntary access to HIV research at Title IV sites.

The Secretary will conduct a review of administrative costs associated with Title IV grantees and issue recommendations and standards for administrative and indirect costs within one year after enactment. It is possible that these standards will lead to a cap on administrative expenses.

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Part F

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

The HIV/AIDS Dental Reimbursement Program assists dental education programs in providing oral health care services to people living with HIV/AIDS. Oral health services are an identified area of significant unmet need for people living with HIV/AIDS. In 1997, the dental program subsidized dental services for 69,000 people living with HIV/AIDS who could not pay for their dental care in 103 dental institutions around the U.S.

➔ **Total funding for 2001:**
\$10 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. SPNSs receive 3% of the funds appropriated to each of the four Titles of Ryan White up to \$25 million each year.

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/AIDS.

AETCs provide ongoing provider education and information each year through an established network of trained providers who are HIV expert resources in their local communities.

➔ **Total funding for 2001:** \$31.6 million

The significant modifications to Part F of the Ryan White CARE Act as a result of reauthorization relate to the

Dental Reimbursement Program and AETCs. Eligibility for the HIV/AIDS Dental Reimbursement Program is expanded to include accredited schools of dental hygiene.

There is also a new initiative, Community-Based Care, which is intended to encourage partnerships with community-based dentists in underserved areas. The AETCs are required to develop protocols for women with HIV, including prenatal and gynecological care, within 90 days of reauthorization.

Conclusion

The 2000 reauthorization of the Ryan White CARE Act affirmed the need for continued federal assistance in combating the AIDS epidemic in the United States. The reauthorization is the result of an attempt to modernize Ryan White 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 reauthorization presents new challenges for Ryan White grantees. The role of the Human Resources and Services Administration in facilitating these changes cannot be underestimated. Community-based organizations, health care providers, and other Ryan White grantees should be vigilant in providing comments on HRSA policy guidance and advocating for capacity building and technical assistance. The various studies that are required by reauthorization will only be successful if they can provide a realistic assessment of the state of data systems and other activities, particularly because many of these studies will result in new requirements for Ryan White grantees. The success of the recent reauthorization of the Ryan White CARE Act is contingent on the cumulative efforts of all of the interested parties committed to serving people living with HIV/AIDS.

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