

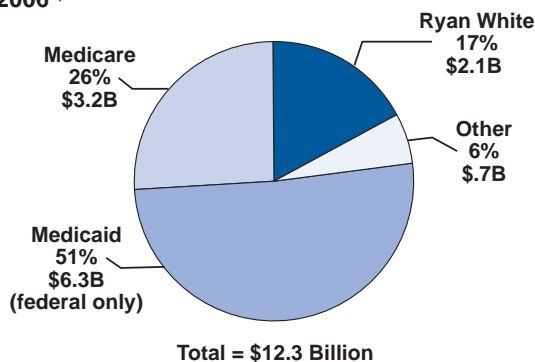
The Ryan White CARE Act

December 2006

The Ryan White CARE Act¹ is the single largest federal program designed specifically for people with HIV/AIDS. Enacted in 1990, the CARE Act provides care and support services to individuals and families affected by HIV/AIDS, functioning as the “payer of last resort”; that is, it fills the gaps in care for those who have no other source of coverage or face coverage limits. Federal CARE Act funding is provided to cities, states,² and directly to providers and other organizations. The CARE Act was reauthorized in 1996 and 2000, and was just reauthorized for the third time in December 2006.³ Whereas all prior authorizations were for five-year periods, the recent authorization extends for three years.

As the number of people living with HIV/AIDS in the U.S. has grown over time, the CARE Act has played an increasingly critical role. Administered by the Health Resources and Services Administration (HRSA), the CARE Act is estimated to reach more than half a million people each year.⁴ It is the third largest source of public financing for HIV/AIDS care in the United States, after Medicaid and Medicare (see Figure 1).^{5,6} Some states and localities also provide funding for Ryan White services (including through state matching funds requirements).

Figure 1: Federal Spending on HIV/AIDS Care by Program, FY 2006^{6,7}



CARE Act Titles, Grantees, & Structure

The CARE Act is comprised of several titles through which funds are provided across the country. The types of entities eligible for federal Ryan White funds vary by title, and include states, cities, and directly-funded public and private providers and other organizations. Most federal CARE Act funding is provided to states (55%) and cities (30%), with the remainder provided directly to organizations.⁸ Much of the funding provided to states and cities is in turn channeled to local providers as well. Community-based organizations (CBOs) make up the largest single group of CARE Act entities serving clients (45% in 2004).⁹

In recognition of the varying nature of the HIV/AIDS epidemic, Ryan White grantees have been given discretion in designing local programs, including setting client eligibility requirements and service priorities. For the first time, however, the recent reauthorization³ of the CARE Act added the requirement that at least 75% of funds be spent on “core medical services” under Titles I-III (see Figure 3), unless a grantee receives a waiver. It also added a requirement for a minimum formulary under the AIDS Drug Assistance Program (ADAP). In addition, funding distribution under Titles I and II will be based on

living HIV and AIDS cases, instead of estimated living AIDS cases (the prior method). Such data will only be permitted from states that have names-based HIV reporting systems; states with code-based systems can receive an exemption, and are allowed up to 4 years to transition to names, but their code-based counts will be reduced for funding purposes in the interim.

The major titles of the CARE Act are (see Figure 2):^{1,3,4}

- **Title I:** Funds “eligible metropolitan areas” (EMAs), those with cumulative total of more than 2,000 reported AIDS cases over the most recent 5-year period, and “transitional grant areas” (TGAs), those with 1,000-1,999 cases, over most recent 5-year period. Two-thirds of funds distributed by formula based on an EMA or TGA’s share of living HIV and AIDS cases; remainder distributed via competitive, supplemental grants based on “demonstrated need”. At least 75% of Title I funds must be spent on core medical services. EMAs must establish Planning Councils, local bodies tasked with assessing needs, establishing a plan for the delivery of HIV care, and developing priorities for the allocation of funds. TGAs are not required to do so (unless they are “grandfathered”¹⁰ EMAs).
- **Title II:** Funds all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 5 other territories and associated jurisdictions. Includes Title II base and supplemental grants, ADAP and ADAP supplemental grants, and Emerging Communities (ECs) grants. States provide services directly or through Title II “Consortia” (a consortium is an association of organizations set up to plan for and deliver HIV care). At least 75% of funds must be spent on core medical services.
 - *Title II Base & Title II Supplemental:* Funds distributed by formula to states based on a state’s share of living HIV and AIDS cases, weighted to reflect the presence or absence of EMAs/TGAs. Title II “supplemental” grants available for states with “demonstrated need.”
 - *ADAP & ADAP Supplemental:* Funds “earmarked” by Congress for state ADAPs to provide medications to people with HIV/AIDS (or pay for health insurance that provides medications). ADAP supplemental grants available to states with “severe need” (5% of earmark reserved).

Figure 2: Ryan White Titles, Funding & Grantees^{3,4,8,11}

Title	FY 2006		Number of Grantees
	\$	%	
Title I	\$611.6	30%	20 EMAs*; 36 TGAs*
Title II	\$1,134.6	55%	59 States/Territories; 21 ECs*
ADAP	(\$789.5)	--	59 States/Territories
Title III	\$196.1	10%	364 EIS, 35 Capacity/Planning
Title IV	\$72.7	4%	94 Grantees
Title VI: AETC	\$34.7	2%	4 National, 11 Regional Centers
Title VI: Dental	\$13.1	1%	68 Reimbursement; 12 Partnership
TOTAL	\$2,062.7	100%	

*Expected number in FY 2007.

- *ECs*: A portion of Title II base funds set-aside for grants to metropolitan areas that do not yet qualify as EMAs or TGAs, but have 500-999 cumulative reported AIDS cases over most recent 5-years. All funding is distributed via formula.
- **Title III**: 75% of funds must be spent on core medical services. Public and private organizations are funded directly for:
 - *Early Intervention Services (EIS)*: to reach people newly diagnosed with HIV. Services include HIV testing, case management, and risk reduction counseling.
 - *Capacity Development & Planning Grants*: supports organizations in planning for service delivery and in building capacity to provide services.
- **Title IV**: Funds public and private organizations directly to provide family-centered and community-based services to children, youth, and women living with HIV and their families. Services include outreach, prevention, primary and specialty medical care, and psychosocial services; also supports activities to improve access to clinical trials and research for these populations.
- **Title VI**: Funds provided for:
 - *Special Projects of National Significance (SPNS)*: projects that address emerging needs of clients and assist in developing standard electronic client information data system.
 - *AIDS Education and Training Centers (AETCs)*: national and regional centers that provide education and training for health care providers who treat people with HIV/AIDS; also funds *dental reimbursement* and *community-based dental partnership programs*.
 - *Minority AIDS Initiative (MAI)*: The MAI, created in 1998 in response to growing concern about the impact of HIV/AIDS on racial and ethnic minorities in the United States, provides funding across several DHHS agencies/programs, including the CARE Act, to strengthen organizational capacity and expand HIV-related services in minority communities. The Ryan White component was codified in the new CARE Act reauthorization. In FY 2006, the MAI was funded at \$391.4 million including \$127.3 million through Ryan White.¹²

Figure 3: List of Core Medical Services (75% of funds under Titles I-III must be spent on core medical services)³

Outpatient and ambulatory health services; medications; 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.

CARE Act Clients

HRSA estimates that more than half a million people receive Ryan White funded services each year, although it is not possible to obtain an unduplicated count of clients because there is currently no client-level data collection system, and many clients receive services from multiple parts of the CARE Act.⁴ Available data indicate that Ryan White programs serve a low-income, underserved population.^{9,13} Nearly three-quarters (72%) of CARE Act clients had annual household incomes equal to or below the poverty level and 31% had no medical insurance in 2004; 55% were covered by public insurance programs.⁹ CARE Act clients are primarily male, between the ages of 25 and 44, and are people of color.^{9,13} Looking at the ADAP program specifically, half (50%) of ADAP clients have incomes at or below the poverty level and nearly three-quarters (73%) are uninsured.¹³

Funding for the CARE Act^{6,8}

Federal funding for the CARE Act began in FY 1991 and increased significantly in the mid-nineties, after the introduction of highly active antiretroviral therapy (HAART). Since FY 1995, funding for Ryan White has tripled, rising from \$633 million to \$2.1 billion in FY 2006,

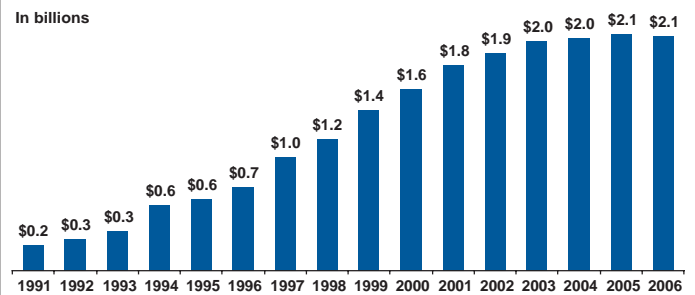
largely reflecting increased funding for medications through ADAP. In recent years, funding increases have leveled, and, for the first time, declined slightly between FY 2005 and FY 2006. The President's FY 2007 budget request includes \$2.16 billion for the CARE Act, which would represent a \$95 million increase over FY 2006. The new funds are part of the President's Domestic AIDS Initiative and include \$70 million for addressing state waiting lists for HIV medications and \$25 million for expanding outreach efforts through HIV community action grants to faith and community-based organizations, and for technical assistance.

The Future Outlook

Ryan White programs will continue to play a critical role for low-income people with HIV/AIDS who have no other source of care, particularly as the number of people living with HIV/AIDS continues to grow and the cost of care increases. However, because Ryan White is a discretionary federal grant program, its funding depends on annual appropriations by Congress, and funding levels do not necessarily correspond to the number of people who need services or the actual costs of services. As a result, some states and communities have been unable to meet the needs of all people living with HIV/AIDS. For example, some state ADAPs have had to institute waiting lists, limit ADAP formularies, and cap client enrollment due to resource constraints.¹³

The recent reauthorization of the CARE Act made significant changes to the program, including setting minimum funding requirements for core medical services, creating new structures for funding, and changing the formula used to distribute funds through Titles I and II.¹⁴ It will be important to monitor the impact of these changes on people with HIV/AIDS, their providers, and communities, as they go into effect next year.

Figure 4: Federal Funding for the Ryan White CARE Act, FY 1991-2006⁸



References

- 1 The Ryan White CARE Act of 1990 [P.L. 101-381] & Amendments of 1996 [P.L. 104-146] and 2000 [P.L. 106-345].
- 2 The term "state" as used here includes territories and associated jurisdictions.
- 3 The Ryan White HIV/AIDS Treatment Modernization Act of 2006 [P.L. 109-415].
- 4 HRSA, HIV/AIDS Bureau, <http://hab.hrsa.gov/programs/factsheets>.
- 5 KFF, *Financing HIV/AIDS Care: A Quilt with Many Holes*, May 2004.
- 6 KFF, Fact Sheet: *U.S. Federal Funding for HIV/AIDS: The FY 2007 Budget Request*, February 2006.
- 7 OMB; CMS Office of the Actuary; HHS Office of Budget, 2006.
- 8 HRSA, HIV/AIDS Bureau, <http://hab.hrsa.gov/reports/funding.htm>.
- 9 HRSA, *Ryan White CARE Act Annual Data Summary* (for Calendar Year 2004), August 2006.
- 10 Grandfathered EMAs are those that move from EMA to TGA status, based on their reported AIDS cases.
- 11 National Alliance of State and Territorial AIDS Directors, December 2006.
- 12 HHS Office of the Budget, February 2006.
- 13 KFF/NASTAD, *National ADAP Monitoring Project Annual Report*, March 2006.
- 14 KFF, "The Ryan White CARE Act: A Side-by-Side Comparison of Prior Law to the Newly Reauthorized CARE Act," www.kff.org/hiv/aids/7531.cfm.

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