

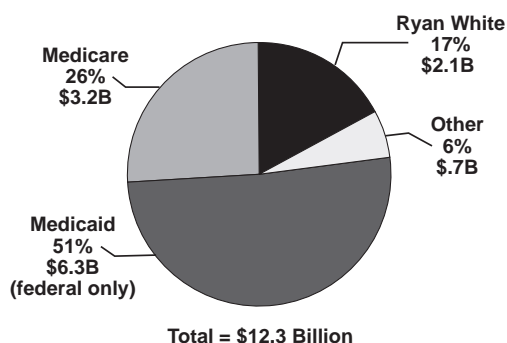
### Ryan White Comprehensive AIDS Resources Emergency Act

November 2006

The Ryan White Comprehensive AIDS Resources Emergency (CARE)<sup>1</sup> Act is the single largest federal program designed specifically for people with HIV/AIDS. First enacted in 1990, and reauthorized in 1996 and 2000, 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,<sup>2</sup> and directly to providers and other organizations.

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.<sup>3</sup> It is the third largest source of public financing for HIV/AIDS care in the United States, after Medicaid and Medicare (see Figure 1).<sup>4,5</sup> 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<sup>5,6</sup>**



#### CARE Act Titles, Grantees, & Structure

The CARE Act is comprised of several parts, or 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.<sup>7</sup> 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).<sup>8</sup>

In recognition of the varying nature of the HIV/AIDS epidemic, Ryan White grantees are given broad discretion in designing local programs, including setting client eligibility requirements and service priorities (these are not mandated under current law). The majority of CARE Act funds are used for health care and support services. For example, in FY 2005, Title I grantees allocated 62% of funds to health care services, 14% to case management, and 24% to support services.<sup>9,10</sup> In FY 2004, 82% of all Title II funds were spent on health care services.<sup>9,11</sup>

The major titles of the CARE Act are (see Figure 2):<sup>3</sup>

- **Part A (Title I):** Funds “eligible metropolitan areas” (EMAs), defined as those most severely affected by HIV/AIDS, as measured by reported AIDS cases over the most recent 5-year period. Half of federal funding is distributed by formula based on an EMA’s share of “estimated living AIDS cases” (ELCs<sup>12</sup>); the remainder is distributed via competitive, supplemental grants based on “severe need.” Title I services include outpatient medical and dental care, case management, and mental health and substance abuse treatment services. The CARE Act requires EMAs to 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.
- **Part B (Title II):** Funds all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 5 territories and associated jurisdictions. Includes Title II base funding, the AIDS Drug Assistance Program (ADAP), 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).
  - *Title II Base:* Funds are distributed by formula to states based on a state’s share of ELCs. Services include direct health and support services, prescription drugs, health insurance purchasing and continuation, home health care, and early intervention activities.
  - *ADAPs:* Funds “earmarked” by Congress for state ADAPs to provide medications to people with HIV/AIDS (or pay for health insurance that provides medications). Also includes an “ADAP supplemental” grant (3% of earmark reserved for grants to states with “severe need”).
  - *ECs:* A portion of Title II base funds is set-aside for grants to metropolitan areas that do not yet qualify as EMAs, but have reached a minimum level of reported AIDS cases.

**Figure 2: Ryan White CARE Act Titles, Funding & Grantees<sup>3,7</sup>**

Part (Title)	FY 2006		Grantees*
	\$	%	
Part A (Title I)	\$611.6	30%	51 Cities
Part B (Title II)	\$1,134.6	55%	59 States/ Territories
ADAP	(\$789.5)	--	--
Part C (Title III)	\$196.1	10%	360 Public/Private Entities**
Part D (Title IV)	\$72.7	4%	91 Public/Private Entities
Part F AETC	\$34.7	2%	4 National, 11 Regional Centers
Part F Dental	\$13.1	1%	68 Public/Private Entities; 15 Demonstrations
<b>TOTAL</b>	<b>\$2,062.7</b>	<b>100%</b>	

\*Represents the number of grantees in FY 2006 for all titles except Title IV, which is the number in FY 2005. \*\*Title III Early Intervention Services grantees.

- **Part C (Title III):** Funds public and private organizations directly for:
  - *Early Intervention Services (EIS):* to reach people newly diagnosed with HIV. Services include HIV testing, case management, and risk reduction counseling.
  - *Planning and Capacity Building Grants:* supports organizations in planning for service delivery and in building capacity to provide services.
- **Part D (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.
- **Part F:** Funds provided for:
  - *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;
  - Dental reimbursement programs and community-based dental programs.
- **Minority AIDS Initiative:** 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 to strengthen organizational capacity and expand HIV-related services in minority communities. It totaled \$391.4 million in FY 2006, including \$127.3 million through the Ryan White CARE Act.<sup>13</sup>
- **Other:** Special Projects of National Significance (SPNS) for innovative demonstration projects.

### 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.<sup>3</sup> Available data indicate that Ryan White programs serve a low-income, underserved population.<sup>8,14</sup> Nearly three-quarters (72%) of CARE Act clients had annual household incomes at or below the poverty level and 31% had no medical insurance in 2004; 55% were covered by public insurance programs.<sup>8</sup> CARE Act clients are primarily male, between the ages of 25 and 44, and the majority are people of color.<sup>8,14</sup> 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.<sup>14</sup>

### Funding for the CARE Act<sup>5,7</sup>

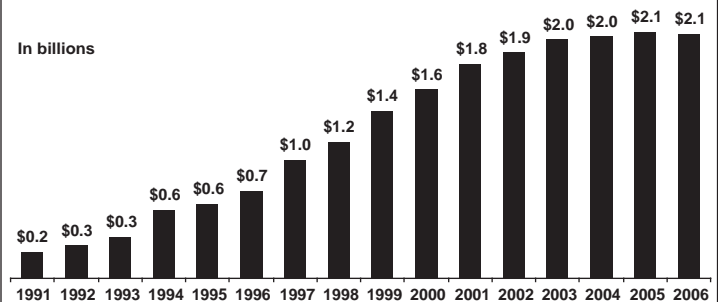
Federal funding for the Ryan White CARE Act began in FY 1991; it increased significantly in the mid-nineties, after the introduction of highly active antiretroviral therapy (HAART) (see Figure 3). Since FY 1995, funding for Ryan White has tripled, rising from \$633 million to \$2.1 billion in FY 2006, 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.<sup>14</sup>

A major issue facing the CARE Act is the timing and content of its next reauthorization.<sup>15</sup> The CARE Act was due to be reauthorized for the third time by the end of FY 2005 but Congress has not yet acted on reauthorization (the program's authority has been extended under current law while discussions continue). To date, several reauthorization bills have been introduced by Congress and the White House released its own principles for reauthorization. Key issues include: changes in the funding distribution formulas for Titles I and II, including the move to using HIV and AIDS cases (vs. just AIDS cases) for determining funding allocations; mandating that 75% of funds be spent on a core set of medical services; and a requirement for a minimum ADAP formulary. Whatever changes will be made will likely have an impact on how funding is distributed across the country and how systems of care are designed in communities.

**Figure 3: Federal Funding for the Ryan White CARE Act, FY 1991–2006<sup>7</sup>**



### 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 HRSA, HIV/AIDS Bureau, <http://hab.hrsa.gov/programs/factsheets>.
- 4 KFF, *Financing HIV/AIDS Care: A Quilt with Many Holes*, May 2004.
- 5 KFF, Fact Sheet: *U.S. Federal Funding for HIV/AIDS: The FY 2007 Budget Request*, February 2006.
- 6 OMB; CMS Office of the Actuary; HHS Office of Budget, 2006.
- 7 HRSA, HIV/AIDS Bureau, <http://hab.hrsa.gov/reports/funding.htm>.
- 8 HRSA, *Ryan White CARE Act Annual Data Summary* (for Calendar Year 2004), August 2006.
- 9 Calculations by KFF based on grantee funding allocations reported at: <http://hab.hrsa.gov/reports/data2b.htm>.
- 10 After excluding administrative and planning costs from the total.
- 11 Includes funding for ADAP, health insurance, health care provided directly by states and through Title II consortia, and early intervention services.
- 12 ELCs are determined by applying defined survival weights by year to the cumulative number of AIDS cases reported over the preceding 10 year period.
- 13 HHS Office of the Budget, February 2006.
- 14 KFF/NASTAD, *National ADAP Monitoring Project Annual Report*, March 2006.
- 15 KFF, "The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act: A Side-by-Side Comparison of Current Law and Reauthorization Proposals," [www.kff.org/hiv/aids/7531.cfm](http://www.kff.org/hiv/aids/7531.cfm).

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