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AIDS: The Ryan White CARE Act

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Summary

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act makes federal funds available to metropolitan areas and states to assist in health care costs and support services for individuals and families affected by the human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS). P.L. 106-345, signed into law in October 2000, reauthorized the act through FY2005. In July 2005, the Bush Administration released its reauthorization principles and an outline of proposed changes to CARE Act programs. Legislation reauthorizing the Ryan White CARE Act is expected to be introduced during the 109th Congress. CARE Act programs received $2.038 billion in FY2006; the request for FY2007 is $2.133 billion, a $95 million increase: $70 million for state grants under Title II and $25 million for Title III grants. This report will be updated periodically.

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Background

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act makes federal funds available to metropolitan areas and states to provide a number of health care services for AIDS patients including medical care, drug treatments, dental care, home health care, and outpatient mental health and substance abuse treatment. The act is administered by the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services (HHS). The act is commonly identified by its legislative Titles I, II, III, and IV. It was enacted as Title XXVI of the Public Health Service (PHS) Act and codified as Parts A, B, C, D, E, and F under 42 U.S.C. § 300ff-111. Funding for the individual titles appears at the end of the report.

Title I/Part A — Emergency Relief Grant Program. Title I provides funds to eligible metropolitan areas (EMAs) with a population of at least 500,000 that have had more than 2,000 reported AIDS cases in the prior five years. Services supported by Title I grants include community-based outpatient medical and dental care, rehabilitative services, home health and hospice care, transportation and housing assistance, nutrition services, and respite care. The program is intended to assist low-income or under-insured people living with HIV. A portion of each grant must be spent on services for women, infants and children with HIV disease. In FY1991, the first year Title I grants were awarded, 16 EMAs were identified; by FY2002, the number of EMAs had increased to the current total of 51.[1]

About half of the Title I appropriation is distributed through formula grants, and the remaining half is distributed via discretionary supplemental grants awarded on the basis of need. Currently, formula grants are distributed to EMAs in proportion to the estimated number of living AIDS cases in each EMA. The number of living AIDS cases is estimated from the number of reported AIDS cases over a 10-year period with weighting factors to reflect that not all reported cases are still alive. Under the 2000 reauthorization (P.L. 106-345), statistics on HIV cases, rather than only on AIDS cases, would be used in the formula for determining Title I grant amounts as early as FY2005 — if the Secretary of HHS finds the HIV incidence data are sufficiently accurate and reliable. In June 2004, the Secretary determined that HIV case reporting is incomplete and cannot be used to distribute CARE Act grants. Under P.L. 106-345, however, cases of HIV disease will be used for determining FY2007 Title I grant amounts.

The hold harmless provision in Title I added in 1996 and changed in 2000 by P.L. 106-345 resulted in some EMAs receiving lower funding. Under the hold

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[1] A list of the 51 Title I EMAs is at [http://hab.hrsa.gov/programs/factsheets/title1fact.htm].

harmless provision in P.L. 106-345, an EMA cannot receive less than a percentage of the Title I formula grant it received in a base year, protecting grantees from large decreases in funding. The base year can be different for each EMA. For an EMA facing a reduction in its formula grant, the base year is the year before the reduction. In the first year after the base year, the EMA cannot receive less than 98% of what it received in a base year. By the fifth year, an EMA cannot receive a formula grant that is less than approximately 87% of what it received in the base year if HIV incidence data are included in the distribution formula, or 85% of what an EMA received in the base year if HIV incidence data are not used in the fifth year. The hold harmless provision no longer applies when an EMA's grant through the formula is equal to or exceeds its hold harmless amount. The hold harmless provision is funded with money that would have been distributed through Title I supplemental grants.

Title I grants are made to the chief elected official of the city or county in the EMA that administers the health agency providing services to the greatest number of persons with HIV. The official must establish an HIV Health Services Planning Council, which sets priorities for care delivery according to federal guidelines. The Council may not be directly involved in the administration of any Title I grant. Membership of the Council must reflect the ethnic and racial make-up of the local HIV epidemic.

Title II/Part B — Care Grant Program. Title II awards formula grants to states and territories for home and community-based health care and support services. Services must be accessible to low-income individuals. Many states use Title II funds to provide services directly or through subcontracts with HIV care consortia. Consortia are associations of public and nonprofit health care and support service providers that assess needs and deliver services to individuals with HIV. Title II grants are also used to provide (1) health insurance coverage for low-income persons through Health Insurance Continuation Programs; and, (2) drug treatments under the AIDS Drug Assistance Programs (ADAPs) for individuals with HIV who have limited or no coverage from private insurance or Medicaid.[2]

The basic Title II grants are awarded based on a formula that takes into account two factors: (1) each state's proportion of the estimated number of living AIDS cases (both inside and outside of Title I EMAs); and (2) each state's proportion of the estimated number of living AIDS cases in the state *who are not in a Title I EMA*. The first factor is given a greater weight (.80) relative to the second factor (.20) when determining the Title II grant amount. Estimated cases of people living with AIDS in EMAs are included in both the allocation formula for Title I and for Title II. As a result, states with EMAs receive a larger amount of money, per case, than states without an EMA.[3]

Under P.L. 106-345, statistics on HIV cases rather than AIDS cases would be used in the formula for determining Title II grant amounts by FY2005, but only if the

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[2] For more on Title II progams see [http://hab.hrsa.gov/programs/factsheets/titleiifact.htm].

[3] U.S. Government Accountability Office. *Ryan White CARE Act: Factors that Impact HIV and AIDS Funding and Client Coverage*. GAO-05-841T. June 2005.

Secretary of HHS determines that the HIV incidence data are sufficiently accurate and reliable. In June 2004, the Secretary determined that HIV case reporting is incomplete and cannot be used to distribute CARE Act grants. Starting in FY2007, cases of HIV disease are to be used for determining Title II grants.

Two provisions can increase the basic Title II grant amount a state or territory receives above what it would receive as a result of the formula alone. A minimum grant provision dictates that no state shall receive less than $200,000 if it has less than 90 estimated living cases of AIDS or $500,000 if it has more than 90 estimated living cases of AIDS. A hold harmless provision dictates that a state shall not receive a grant that is less than a specified percentage of what it received in FY2000. These two provisions are funded by reducing the grant amounts received by all states and territories that do not receive a minimum grant amount or hold harmless grant amount. States with more than 1% of the total AIDS cases reported nationally must contribute state matching funds based on a formula. Grants may not be made to any state that does not make a good faith effort to notify a spouse of an HIV-infected patient that the spouse should seek testing. States must use a portion of each Title II grant on services for women, infants and children with AIDS.

P.L. 106-345 created a supplemental grant for states with metropolitan areas in which 500 to 1,999 cases of AIDS have been reported in the five most recent calendar years. These areas do not qualify for Title I funding. Approximately 0.1% of Title II funds are distributed among these "emerging communities." Half of the money is distributed among emerging communities with between 500 and 999 reported cases, and half is distributed among emerging communities with 1,000 to 1,999 reported cases. The grant is based on each area's proportion of the total number of cases in all eligible areas.

P.L. 106-345 changed the way funds would be allocated to states for the AIDS Drug Assistance Programs (ADAPs). Prior to P.L. 106-345, ADAP funds were distributed among states based on each state's proportion of AIDS cases. Under P.L. 106-345, a new grant program distributes 3% of ADAP funds to states that demonstrate a severe need to increase the availability of drugs. Criteria for awarding these grants are developed by the Secretary, taking into account eligibility standards, formulary composition, and the number of HIV-positive individuals not receiving drugs who are at or below 200% of the federal poverty level. The remaining 97% of ADAP funds are distributed based on each state's proportion of AIDS cases. Many states have implemented cost containment measures, such as waiting lists, due to insufficient ADAP funds. On June 23, 2004, the Bush Administration announced a $20 million initiative for 10 states with ADAP waiting lists (Alabama, Alaska, Colorado, Idaho, Iowa, Kentucky, Montana, North Carolina, South Dakota, and West Virginia); funding is expected to run out in March 2006. According to the National Alliance of State and Territorial AIDS Directors, as of January 18, 2006, 954 individuals were on ADAP waiting lists in ten states; 118 of these individuals are receiving medications through the $20 million initiative.[4]

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[4] NASTAD, The ADAP Watch, Feb. 1, 2006 [http://www.nastad.org/documents/public/publicpolicy/2006-02-NASTAD_ADAP_Watch.pdf].

Title III/Part C — Early Intervention Services. Title III provides early intervention grants to public and private nonprofit entities already providing primary care services to low-income and medically underserved people at risk for HIV. Title III grants are awarded to community and migrant health centers, homeless programs, local health departments, family planning programs, hemophilia diagnostic and treatment centers and other nonprofit community-based programs. Title III services include HIV testing, risk reduction counseling, case management, outreach, medical evaluation, transmission prevention, oral health, nutritional and mental health services, and clinical care.

Title IV/Part D — General Provisions. In its original enactment, Title IV authorized a number of different HIV-related programs; only one was ever funded: the pediatric demonstration grants. In the CARE Act's 1996 reauthorization, the pediatric demonstration grant program was replaced with a program of grants for coordinated services and access to research for women, infants, children, and youth. The grants enhance access to and linkage with clinical research supported by the National Institutes of Health (NIH), and are to be made in coordination with the NIH activities. The grants provide opportunities for women, infants, children, and youth to be voluntary participants in research of potential clinical benefit to individuals with HIV. Such individuals are provided health care on an outpatient basis, case management, referrals, transportation, child care, and other incidental services to enable participation.

Part E. Part E authorizes grants for emergency response employees and establishes procedures for notifications of infectious diseases exposure; Part E has never been funded.

Part F — Demonstration and Training. Part F provides support for the Special Projects of National Significance (SPNS) Program, the AIDS Dental Reimbursement (ADR) Program and the AIDS Education and Training Centers (AETCs). The SPNS program awards grants to public and nonprofit private entities for the development of innovative models of HIV/AIDS care, especially programs that deliver care to minority and hard-to-reach populations. Under current statute, the SPNS program is to be funded, up to $25 million, from amounts appropriated for Titles I, II, III, and IV. However, beginning in FY2003, each Labor-HHS Appropriation bill has provided $25 million for the SPNS program via a funding mechanism known as the "PHS evaluation tap." The tap, authorized under section 241 of the PHS Act, transfers money among PHS agencies for particular activities as specified by the appropriators.[5] The ADR program reimburses dental schools for their treatment of AIDS patients. The AETC program provides training for health providers in the prevention of perinatal HIV transmission and prevention and treatment of opportunistic infections. Both the dental and the AETC programs were transferred legislatively from Title VII of the PHS Act.

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[5] Although section 241 [42 USC 238j] states that the evaluation tap should be no more than 1% of PHS program appropriations, the conference reports for the LHHS Appropriation acts have set the tap at not more than 2.1% in FY2003 (H.Rept.108-10), 2.2% in FY2004 (H.Rept.108-401), 2.4% in FY2005 (H.Rept.108-792), and 2.4% in FY2006 (H.Rept. 109-337).

Reauthorization

The CARE Act was signed into law in 1990 (P.L. 101-511) and reauthorized and amended in 1996 (P.L. 104-146) and 2000 (P.L. 106-345). P.L. 106-345 retained the basic structure of the Ryan White CARE Act but changed the formulas used to distribute Title I and Title II grants. Additional changes made by P.L. 106-345 to the CARE program included the following: (1) requirements are established for the development of epidemiologic measures to identify HIV-infected individuals not currently in care; (2) incentives are provided to states for HIV testing of pregnant women and infants; (3) incentives are established for implementing a partner notification program; (4) requirements are set for the development of quality management programs; (5) requirements are established for the development of a plan for the medical case management of HIV-positive prisoners who are released from custody; (6) requirements are included regarding the development of rapid HIV tests; (7) and additional grants are provided to metropolitan areas with between 500 and 1,999 reported cases of AIDS over the previous five-year period.

In P.L. 106-345, Congress asked that the Institute of Medicine (IOM) conduct a study to assess whether current allocation strategies equitably and efficiently distribute CARE Act funds to areas with the greatest need, and whether quality of care can be refined and expanded. IOM published the study, *Measuring What Matters*, in 2004.[6] IOM evaluated whether the HIV case data reported by the states to the Centers for Disease Control and Prevention are sufficiently accurate and reliable for inclusion in the Title I and II formula grants, and found that states are not equally capable of providing high-quality HIV data. IOM made three recommendations based on this finding: that HRSA continue to use estimated living AIDS cases in the formulas for at least the next four years, that efforts to improve the quality of HIV data continue, and that additional studies be conducted to examine the comparability of HIV reporting data across states for the purpose of allocating resources. IOM also evaluated how effectively CARE Act programs provide funds to areas of severe need. Factors other than estimated living AIDS cases are used to assess severity of need — HRSA has relied on a qualitative assessment process. IOM recommended methods of incorporating a more quantitative measure of resource needs within the grant application process. Lastly, IOM evaluated the efforts by HRSA and CARE Act grantees to incorporate improvements in the quality of care received by HIV-infected individuals. IOM found that, overall, HRSA and the clinics and programs funded by the CARE Act are doing an admirable job of defining, assessing and trying to improve the quality of patient care. However, IOM recommended additional steps to measure and improve quality of care.

In July 2005, the Bush Administration released a set of five reauthorization principles: serve the neediest first, focus on life-extending services, increase

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[6] Institute of Medicine, *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*, The National Academies Press, Washington, D.C., 2004.

prevention efforts, increase accountability, and increase flexibility.[7] The administration also made a number of specific proposals: 75% of CARE Act funds should be spent on core medical services; a priority list of core HIV/AIDS medications for federal funding should be developed; the hold harmless provisions should be eliminated; double counting of HIV/AIDS cases between states and metropolitan areas should be eliminated; and unallocated balances should revert to the Secretary of HHS for redistribution to states with the greatest need. Legislation reauthorizing the Ryan White CARE Act is expected to be introduced during the 109th Congress.

Table 1. Federal Funding for the Ryan White CARE Act

($ in millions)

	Title I	**Title II**	**(ADAP) (non-add)**	**Title III**	**Title IV**	**Part E**	**Part F AETC**	**Part F ADR**	**Total**
FY1991	87.8	87.8	—	44.9	19.5	0	17.0	—	257.0
FY1992	121.6	107.6	—	48.7	19.3	0	16.9	—	314.1
FY1993	184.8	115.3	—	48.0	20.9	0	16.4	—	385.4
FY1994	325.5	183.9	—	48.0	22.0	0	16.4	7.0	602.8
FY1995	356.5	198.1	—	52.0	26.0	0	16.3	6.9	655.8
FY1996	391.7	260.8	(52)	57.0	29.0	0	12.0	6.9	757.4
FY1997	449.8	417.0	(167)	69.6	36.0	0	16.3	7.5	996.3
FY1998	464.7	542.8	(285.5)	76.2	40.8	0	17.2	7.8	1,150.2
FY1999	505.0	737.7	(461.0)	94.3	46.0	0	20.0	7.8	1,410.9
FY2000	546.3	823.8	(528.0)	138.4	50.0	0	26.6	8.0	1,594.6
FY2001	604.2	910.9	(589.0)	185.9	65.0	0	31.6	10.0	1,807.6
FY2002	619.4	977.2	(639.0)	193.8	71.0	0	35.3	13.5	1,910.2
FY2003*	618.7	1,053.4	(714.3)	198.4	73.6	0	35.6	13.4	1,993.0
FY2004*	615.0	1,085.9	(748.9)	197.2	73.1	0	35.3	13.3	2,019.9
FY2005*	610.1	1,121.8	(787.5)	195.6	72.5	0	35.1	13.2	2,048.3
FY2006**	604.0	1,120.5	(789.5)	193.6	71.8	0	34.7	13.1	2,037.7
FY2007 Request***	604.0	1,190.5	(789.5)	218.6	71.8	0	34.7	13.1	2,132.7

Source: FY2005 and FY2006 Conference amounts are found in the Conference Report for H.R. 3010 (H.Rept. 109-337). FY2006 and FY2007 Request amounts found in the HRSA FY2007 Justification document. May not add due to rounding.

Note: The total does not include $25 million for SPNS provided via the PHS program evaluation tap (section 241 of the PHS Act).

**FY2006 amount includes the 1% rescission and does not include the $25 million for SPNS.

***FY2007 Request does not include $25 million for SPNS.

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[7] Fact Sheet, Ryan White Care Act Reauthorization Principles, July 27, 2005, found at [http://www.hhs.gov/news/press/2005pres/ryanwhite.html].