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Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990

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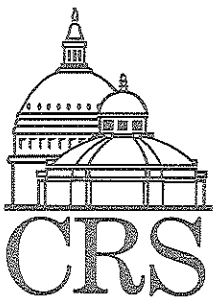

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RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY(CARE) ACT OF 1990

SUMMARY

This report provides an overview of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 (P.L. 101-381), a four part Federal grant program designed to provide emergency relief and essential health care services to persons afflicted with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). The Act, administered by the Health Resources and Services Administration (HRSA), focuses primarily on treatment and treatment-related services and authorizes appropriations through FY 1995.

Programs authorized under the Ryan White Act provide emergency assistance to localities disproportionately affected by the HIV epidemic. Grants are made to States, metropolitan areas, and other public or private nonprofit entities to provide for the development, organization, coordination, and operation of more effective and cost efficient services for individuals and families with HIV disease.

Title I of the Act provides emergency formula and supplemental grants to disproportionately affected, eligible metropolitan areas (EMAs). Thirty-four EMAs received funds for FY 1994 and an estimated three to seven new EMAs could be added for FY 1995. Title I funds are directed to the chief elected official administering the public health agency providing outpatient and ambulatory services to the greatest number of persons with AIDS in the designated area. The official must establish an HIV Health Services Planning Council which further sets priorities for care delivery in accord with Federal guidelines.

Title II provides formula grants to States and Territories for comprehensive care services including home and community-based care, continuity of health insurance coverage, treatments to prevent deterioration of health, and other services. States reporting 1 percent or more of the national AIDS caseload are required to match Federal funds ($1 State for every $2 Federal in 1994) and must use 50 percent or more of their grant toward establishing an HIV health and support services consortium. Title II grants also support Special Projects of National Significance (SPNS), a program which promotes advancements in the delivery of health care and support services to the HIV population.

Title III(b) provides early intervention categorical grants to public and private nonprofit entities already providing primary care services to populations at risk of HIV. Services allowed under title III(b) include counseling and testing, case management, outreach, medical evaluation, transmission prevention, and risk reduction strategies.

Title IV pediatric demonstration grants were funded under the CARE Act for the first time in FY 1994. These grants foster collaboration and coordination between clinical research and health care providers and target HIV infected children, pregnant women, and their families.

Appropriations for all titles under the Act increased from $220.5 million in FY 1991 to $579.4 million in FY 1994. The President's FY 1995 budget includes an appropriation request of $672 million which, if approved, would constitute a 16 percent, or $92 million increase over FY 1994. Several HRSA evaluations of CARE Act programs were complete or underway during 1993 and the Office of Inspector General (OIG) recently published a draft report evaluating the Act's funding formulas.

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INTRODUCTION

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990[1] is a four part Federal grant program designed to provide emergency relief and essential health care services to persons afflicted with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). The Act focuses primarily on treatment and treatment-related services and authorizes appropriations through 1995. Appropriations for FY 1994 were $579.4 million.[2]

According to one estimate, between 800,000 and 1.2 million individuals are infected with HIV in the United States. As of September 1993, over 339,000 cases of AIDS had been reported to the Centers for Disease Control (CDC).[3] The HIV infection is now the leading cause of death among males aged 25-44 and the fourth leading cause among females of the same group.[4] The average annual cost of treating a person with AIDS has been estimated as $38,300[5] and the number of persons with AIDS who were without health insurance has been estimated at 29 percent.[6]

Federal response to the HIV epidemic spans several government agencies. This report provides an overview of the Ryan White CARE Act, a program administered by the Health Resources and Services Administration (HRSA) under the Public Health Service.

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[1]P.L. 101-381, Aug. 18, 1990 (title XXVI of the Public Health Service Act).

[2]Table 4, on page 7, shows annual authorizations and appropriations for all titles under the program.

[3]U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, v. 5, no. 3, Oct. 1993.

[4]U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *Current Trends Update: Mortality Attributable to HIV Infection among Persons Aged 25-44, U.S. 1991 and 1992.* Morbidity and Mortality Weekly Report, Nov. 11, 1993.

[5]Hellinger, F.J. *Forecasts of the Costs of Medical Care for Persons with HIV: 1992-1995*, Inquiry, v. 29, no. 3, fall 1992. p. 356-365.

[6]National Commission on Acquired Immune Deficiency Syndrome. *America Living with AIDS*. 1991. p. 70.

PURPOSE

The CARE Act provides emergency assistance to localities disproportionately affected by the HIV epidemic. Grants are made to States, metropolitan areas, and other public or private nonprofit entities to provide for the development, organization, coordination, and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease.

Currently, four programs under the Act have been funded. Title I provides emergency assistance to disproportionately affected, eligible metropolitan areas (EMAs), title II provides comprehensive care grants to States and territories, title III(b) provides direct grants to public and private nonprofit entities for early intervention services, and title IV provides for pediatric AIDS demonstration projects.[7]

Title I: HIV Emergency Relief Grant

Title I provides emergency relief, in the form of formula and supplemental grants for case management and comprehensive treatment services to EMAs disproportionately affected by the epidemic. Areas with more than 2,000 cases of AIDS, or where the cumulative per capita incidence exceeds one quarter of 1 percent (.0025), may apply for title I funds. The grants are intended to "supplement," not "supplant" State funds and have the express purpose of enhancing HIV-related ambulatory health and support services at the outpatient level and case management services that prevent unnecessary hospitalization at the inpatient level of services. Fifty percent of title I funds are

TABLE 1. FY 1994 Title I Formula Grant Appropriations

EMAs Approved FY 1991	
Atlanta, GA	$4,066,100
Boston, MA	3,091,900
Chicago, IL	4,706,700
Dallas, TX	3,445,200
Fort Lauderdale, FL	3,555,400
Houston, TX	5,676,800
Jersey City, NJ	2,306,300
Los Angeles, CA	12,617,300
Miami, FL	6,875,100
New York, NY	45,835,400
Newark, NJ	5,166,300
Philadelphia, PA	3,479,500
San Diego, CA	2,696,900
San Francisco, CA	19,057,000
San Juan, PR	4,561,200
Washington, D.C.	5,225,900
EMAs Added FY 1992	
Baltimore, MD	2,232,400
Oakland, CA	2,379,500
EMAs Added FY 1993	
Detroit, MI	1,623,500
Nassau-Suffolk, NY	1,403,900
New Orleans, LA	1,691,900
Orange Co, CA	1,426,900
Pounce, PR	976,800
Seattle, WA	1,617,900
Tampa-St.Pete, FL	1,955,300
EMAs Added FY 1994	
Bergen-Passaic, NJ	1,277,000
Denver, CO	1,626,800
Kansas City, MO	1,251,700
New Haven, CN	1,235,400
Orlando, FL	1,319,900
Phoenix, AZ	1,176,000
Riverside-San Bernardino, CA	1,299,000
St. Louis, MO	1,178,000
W. Palm Beach, FL	1,959,900

Source: Health Resources and Services Administration

[7]Title III(a) early intervention formula grants have never received appropriations. Congress has continued to fund related activities under general authority of the Public Health Service Act. Provisions under title IV not receiving appropriations pertain to the research, evaluation, assessment, and coordination of HIV-related health and support services and model curriculum for emergency response employees. Some of the activities authorized are being carried out by PHS agencies under general appropriations.

allocated by formula, the remaining 50 percent is awarded competitively in the form of supplemental grants.[8]

There are currently 34 EMAs approved for title I funds. Sixteen EMAs received grants originally. Baltimore, MD and Oakland, CA were added for FY 1992 and seven more areas became eligible for FY 1993. Nine EMAs have been added for this year bringing the total to 34. Table 1 shows FY 1994 title I allocations to EMAs and the year each EMA became eligible under the program. An estimated three to seven new EMAs could be added for FY 1995.

Title I funds are directed to the chief elected official administering the public health agency providing outpatient and ambulatory services to the greatest number of persons with AIDS in the designated area. The official must establish an HIV Health Services Planning Council which further sets priorities for care delivery in accord with Federal guidelines. The Council must consist of representatives from a minimum of 11 specific groups. Included among the groups are health care providers, community-based and AIDS service organizations, social service providers, mental health care providers, local public health agencies, hospital and health care planning agencies, representatives of State government, affected community members (including persons infected with HIV), non-elected community leaders, entities receiving grants under the early intervention component (title III) of the Act, and the lead agency from any HRSA demonstration grant operating in the area.

Title II: HIV CARE Grant

Title II formula grants are made to States and territories. The funds are designed to improve the quality, availability, and organization of health care and support services. In FY 1994, 50 States, 3 territories, and the District of Columbia will receive funds under the program.

Allocation of funds is based on the number of AIDS cases reported to CDC for the 2 most recent fiscal years and the average per capita income of the State relative to national per capita income, with the minimum grant set at $100,000.

The focus of title II is comprehensive care and essential services. The grants provide for home and community-based care, continuity of health insurance coverage, and treatments to prolong life or prevent the deterioration of health (e.g., pharmaceuticals). States are required to use 15 percent of their grant to provide health and support services to infants, children, women and families with HIV disease. Eligible areas, excluding Puerto Rico, that report more than 1 percent of total AIDS cases during the 2 fiscal years preceding the grant must match Federal contributions at a rate of $1 State for $2 Federal during fiscal 1994 and must use 50 percent of their CARE grant toward an HIV health and support services consortium in areas where the greatest number of HIV patients live.

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[8]Applications are received and awards are made annually for all titles under the program. Additional information on the grants process can be obtained from the Bureau of Health Resources Development, HRSA.

TABLE 2. FY 1994 Title II Formula Grant Appropriations

Alabama	$ 1,421,700	Nebraska	292,200
Alaska	100,000	Nevada	925,000
Arizona	1,855,500	New Hampshire	160,100
Arkansas	822,000	New Jersey	6,651,100
California	28,174,800	New Mexico	485,800
Colorado	1,794,700	New York	26,128,000
Connecticut	2,246,300	North Carolina	1,996,200
Delaware	515,100	North Dakota	100,000
District of Columbia	2,155,900	Ohio	2,288,900
Florida	16,362,900	Oklahoma	1,133,800
Georgia	4,527,800	Oregon	1,171,000
Hawaii	545,500	Pennsylvania	4,422,300
Idaho	130,100	Rhode Island	452,600
Illinois	5,364,300	South Carolina	2,092,000
Indiana	1,395,000	South Dakota	100,000
Iowa	333,800	Tennessee	1,675,500
Kansas	605,200	Texas	11,814,700
Kentucky	641,800	Utah	511,100
Louisiana	2,494,600	Vermont	100,000
Maine	205,400	Virginia	2,622,600
Maryland	3,626,200	Washington	2,262,800
Massachusetts	3,502,200	West Virginia	173,900
Michigan	2,874,200	Wisconsin	1,069,800
Minnesota	970,500	Wyoming	100,000
Mississippi	900,200	Puerto Rico	7,522,200
Missouri	2,716,300	Guam	3,400
Montana	100,000	Virgin Islands	68,700

Source: Health Resources and Services Administration

Nineteen States currently fall under this requirement. Other States may choose to establish and operate an HIV consortium, defined as "an association of one or more public, and one or more nonprofit private health care and support service providers and community-based organizations" that delivers care to areas most affected by the disease.[9]

According to HHS, 41 States or territories supported HIV care consortia in FY 1992. Forty-eight used title II funds for AIDS/HIV treatments, 27 supported home and community-based care, and 17 assisted with the continuation of health care insurance coverage.

The Secretary is authorized to withhold 10 percent of title II appropriations before allocation to States in order to fund Special Projects of National Significance (SPNS). Any public or private non-profit organization, including community-based organizations, can become eligible and grants are usually awarded for a 3-year cycle.

The program supports projects contributing to the advancement of health care and support services delivery for the HIV population. In the first 2 years of the program,

[9]P.L. 101-381, sec. 2613(a)(1).

priority was given to projects that improved access to care and/or addressed problems such as advocacy, social isolation, quality of life, and mental health.[10]

Table 2 shows FY 1994 title II formula grants by State or territory.

Title III(b): Early Intervention Services

Title III(b)[11] provides categorical grants for outpatient early intervention services. Grants are made to certain organizations already providing comprehensive primary care to populations at risk of HIV. Migrant health centers, community health centers, health care for the homeless grantees, family planning grantees, comprehensive hemophilia diagnostic and treatment centers, federally qualified health centers, and other private nonprofit organizations can become eligible.

Services allowed under title III(b) include counseling and testing, case management, outreach, medical evaluation, transmission prevention, and risk reduction strategies. One hundred thirty-six grantees received funds during FY 1993 and 96,000 persons were expected to be served.

TABLE 3. Title III(b) HIV Early Intervention FY 1992

USER ETHNICITY	
White	**46%**
Black	**41%**
Hispanic	**12%**
Asian	**1%**
CLIENT RISK	
Heterosexual	**35%**
IV Drug Users	**28%**
Male Homo./Bisexual	**21%**
IV Drug Users and Homo./Bisexual	**3%**
Perinatal	**3%**
Hemophiliacs	**2%**
Other	**8%**

Source: Department of Health and Human Services, Justification of Estimates for Appropriations Committees, FY 1994.

Table 3 shows ethnicity and client use of title III(b) services based on a survey of FY 1992 grantees. Preliminary survey results for FY 1993 grantees indicate nearly 69 percent of title III(b) clients were between the ages of 20 and 39 and 50 percent were female.

Title IV: General Provisions

Authorized for appropriations under title IV are pediatric demonstration grants and other provisions relating to the research, evaluation, assessment, and coordination of HIV-related health and support services.

Pediatric Demonstration Grants under title IV target HIV infected children, pregnant women, and their families. In coordination with the National Institutes of Health, the grants encourage innovative models that foster collaboration and coordination between clinical research and health care providers. This title will be funded for the first time in

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[10]For more specific criteria on the SPNS or other CARE Act programs, see Health Resources and Services Administration. Bureau of Health Resources Development. *The Ryan White Comprehensive AIDS Resources Emergency Act of 1990.* Aug. 1993.

[11]Title III(a), providing early intervention formula grants to States, has never been funded.

FY 1994 (previous pediatric HIV demonstrations have been funded under general Public Health Service authorizations).

Title IV, subtitle II contains provisions regarding the notification of exposure to infectious diseases for emergency response employees and authorizes $5,000,000 for FYs 1991-1995 toward the initial implementation of model curriculum. Appropriations for this subtitle have not been made.

PROGRAM AUTHORIZATION

P.L. 101-381 authorizes all titles of the CARE Act through FY 1995 (such sums as necessary for titles I-IV). The program is funded annually under the Labor, HHS, Education appropriation (the FY 1994 appropriation bill, H.R. 2518, became P.L. 103-112 on October 21, 1993).

FY 1995 BUDGET REQUEST

The President's FY 1995 budget includes an appropriation request of $672 million for Ryan White programs. If appropriated, the request would constitute a 16 percent, or $92 million increase over FY 1994.

EVALUATION OF THE PROGRAM

Evaluations of the program have focused on four key areas: allocation of funds to priority needs, inclusion of relevant parties in planning and priority setting, the extent to which services have been received by targeted populations, and the quality and availability of services.

Numerous HRSA evaluations were completed or under way during FY 1993. An evaluation of six HIV-service consortia found approaches to be varied, but effective in building networks for service delivery. In particular, progress was found in the implementation of case management and the linking of clients with primary and home health care services. A longitudinal assessment of community HIV/AIDS services in Baltimore and Oakland, which initially measured provider services and client perceptions of service barriers, has entered it's second phase. An evaluation of how the needs of women with HIV are being addressed in the title I planning process and an identification and description of HIV service delivery systems in rural areas are also in process.

HRSA has sponsored a series of HIV services access work groups concerned with identifying barriers to care for various ethnic, racial, economic, and gender groups. Work groups are comprised of between 10 and 20 invited participants representative of the above populations and include service providers, people living with AIDS, and health services researchers. Strategies recommended by the work groups aid in determining the focus of evaluation projects.

The HHS Office of the Inspector General (OIG) is conducting a series of studies evaluating the effectiveness of Ryan White formulas. Formulas govern half of title I and

all of title II funds, the preponderance of the Act's appropriation. Concerns have been raised that distributions under the current formulas may be leading to disparities in funding, a matter that could be of importance during the reauthorization process.

TABLE 4. Authorization and Appropriations
Ryan White CARE Act
($ in millions)

	1991	1992	1993	1994	1995 Request
Title I					
Authorization	275.0	275.0	Indefinite	Indefinite	Indefinite
Appropriation	87.8	121.7	184.8	325.5	364
Title II					
Authorization	275.0	275.0	Indefinite	Indefinite	Indefinite
Appropriation	87.8	107.7	115.3	183.9	214
Title III					
Authorization	305.0	Indefinite	Indefinite	Indefinite	Indefinite
Appropriation	44.9	49.9	48	48	67
Title IV[a]					
Authorization	20.0	Indefinite	Indefinite	Indefinite	Indefinite
Appropriation	0	0	0	22.0	27

[a]Funding for pediatric demonstration grants only.

Source: Health Resources and Services Admininstration.

FOR RELATED INFORMATION:

U.S. Department of Health and Human Services. Public Health Service. Health Resources and Services Administration. Bureau of Health Resources Development. *The Ryan white comprehensive AIDS resources emergency act of 1990.* Aug. 1993.

U.S. Library of Congress. Congressional Research Service. *Federal funding for AIDS research and prevention: FY 1981-FY 1994.* CRS Report for Congress No. 93-340 SPR, by Judith Johnson. Washington, 1993.