

THE CHALLENGE AHEAD: Renewing the Ryan White CARE Act in 2000

**AIDS Alliance
for Children, Youth & Families**

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Children Affected by AIDS Foundation



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About the Children Affected by AIDS Foundation (CAAF)

CAAF is a 501(c)3 grant-making foundation whose mission is to make a positive difference in the lives of children infected with HIV and affected by AIDS in this country by helping to meet their multifaceted direct care needs, advocating and educating on their behalf, and bringing joy and fun into their lives.

With the generous support of individuals and corporations, some of the ways CAAF has made a difference include:

- providing toys and books that bring laughter and hope to children in hospitals, doctor's waiting rooms, and respite day-care centers;
- ensuring children with HIV receive the health care, medication, and nutritional supplements they need to stay healthy;
- sending children with AIDS to summer and weekend camps;
- supporting safe, clean day-care centers and overnight shelters where children can stay while their parents are in the hospital or at medical appointments;
- funding permanency programs that find loving, new homes for children when their parents have died from AIDS;
- supporting public policy research and advocacy efforts that help improve the lives of HIV-affected children and their families.

CAAF is proud to be a supporter of AIDS Alliance for Children, Youth & Families. CAAF was the sponsor of AIDS Alliance's national meeting, *Voices*, held May 17-19, 1998.

About AIDS Alliance for Children, Youth & Families

AIDS Alliance for Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk children, youth, women, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. Organizational members include over 350 community-based agencies in 27 states, the District of Columbia, and Puerto Rico. Individual members include young people, women, and family members throughout the United States. Many of AIDS Alliance's members provide or receive services funded by Title IV of the Ryan White CARE Act.

AIDS Alliance is a 501(c)(3) non-profit organization. Our board of directors is comprised of HIV service providers, researchers, and policy experts as well as HIV-affected young people, women, and family members.

Foreword

Since 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has been the foundation of federal support dedicated to people living with HIV and AIDS. Hundreds of thousands of Americans rely on programs funded by the CARE Act for critical services such as primary medical care, treatment access, and case management. By increasing access to cutting-edge care and treatment, the CARE Act has enabled thousands of people to benefit from the promising new treatments for HIV.

In 1996, Congress reauthorized, or renewed, the Ryan White CARE Act until September 30, 2000. Although this date may seem distant, it is already time to start asking important questions about the future of the CARE Act. How well is the CARE Act addressing the needs of people living with HIV/AIDS? How well does it serve children, youth, women and families? How can it be improved?

AIDS Alliance has produced *The Challenge Ahead: Renewing the Ryan White CARE Act in 2000* as a resource for understanding the CARE Act and some of the issues that will be critically important when it is reauthorized by Congress. We take a special look at issues affecting children, young people, women, and their families, including the Ryan White Title IV program. We hope that this brief monograph will help spur important discussions in the community about the CARE Act's future.

This document reflects the contributions of many people. The inspiration for this project was a lively plenary session on CARE Act Reauthorization that was held at AIDS Alliance's conference, *Voices '98*. Thank you to facilitator Dorothy Mann and panelists Humberto Cruz, Dorothy Keville, Demetri Moshoyannis, Jacque Muther, Gigi Nicks, and John Palenicek. Thanks also to AIDS Alliance's Board of Directors and board advisory committee members, and to our staff: Clark Moore, who was the lead writer of this document, Laquitta Bowers, Tonia Dickerson, and Evan Gidney. We also appreciate all those who provided comments on draft versions of this monograph.

We would particularly like to acknowledge the contributions of the Children Affected by AIDS Foundation. Our annual conference and this document would not have been possible without their generous support.

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President, Board of Directors

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Executive Director

Introduction

Since its enactment in 1990, the Ryan White CARE Act has enabled communities across the country to provide care and support for people who are living with HIV/AIDS. The CARE Act supports a wide range of community-based services, including primary and home health care, access to medications, case management, substance abuse treatment, mental health services, dental care, nutritional services, and housing. As the number of people requiring HIV/AIDS services had increased, the CARE Act has grown from a \$220.5 million program in fiscal year (FY) 1991 to a \$1.41 billion program in FY 1999.

The Ryan White CARE Act is not the only federal program that provides assistance to people with HIV. In fact, according to a recent analysis, the CARE Act only accounts for about 18.6% of all federal spending on programs that deliver health care, support services, and disability assistance to people with HIV. However, the CARE Act is the largest discretionary federal program that is dedicated to HIV care and treatment.¹

In 1996, the Ryan White CARE Act was reauthorized until September 30 of the year 2000. It is expected that Congress will begin work on reauthorization in early 1999. Discussions are now underway among HIV/AIDS advocates about issues, priorities, and strategies related to the next reauthorization.

The CARE Act reauthorization will be a high priority for AIDS Alliance. Our main goal is to help ensure that the reauthorized CARE Act meets the needs of children, youth, women, and families affected by HIV. We also hope to facilitate the active involvement of our constituents in the reauthorization process. This document is intended to help youth, women and families affected by HIV, their service providers and advocates to understand the current dimensions of the epidemic, the structure of the Ryan White CARE Act, and some of the key issues that will arise during the reauthorization process. We will also share some ideas about how to get involved in the reauthorization process.

Children, Youth, Women and Families in the HIV Epidemic

Since the early 1980s, the HIV epidemic has been one of our nation's most pressing challenges. By the end of 1997, 641,000 Americans had been reported with AIDS, and at least 390,000 had died.² The Centers for Disease Control estimates that between 650,000 and 900,000 Americans are living with HIV, and at least 40,000 new infections occur each year.³ In 1997, AIDS was the fifth leading cause of death for Americans ages 25-44.⁴ It is difficult to estimate the enormous costs of diagnosing, treating, and caring for people living with

¹ Scott Foster et al., *Federal HIV/AIDS Spending: A Budget Chartbook* (Menlo Park, CA: Kaiser Family Foundation, 1998) 26-27.

² Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 9.2*: 9-19.

³ Centers for Disease Control and Prevention, *Trends in the HIV & AIDS Epidemic* (Atlanta: CDC, 1998) 2.

⁴ Centers for Disease Control and Prevention, "Births and Deaths: Preliminary Data for 1997," *National Vital Statistics Report 47.4* (Oct. 1998): 33.

HIV/AIDS, and impossible to fully assess or describe the extent of human suffering and lost potential caused by the disease.

Reauthorization of the CARE Act will occur in the context of a rapidly changing epidemic. In 1996, the number of new AIDS cases and deaths in the U.S. dropped for the first time. This reversal was primarily the result of new treatment options for HIV, which are helping many people with HIV to live longer, healthier lives. Unfortunately, these treatments are very expensive, require complex dosing schedules, often cause severe side effects, and require intensive medical monitoring. In addition, increasing numbers of people with HIV are developing resistance to some or all of the currently available AIDS drugs. As people with HIV live longer and require more complex medical care and support services, the demand for specialized HIV care and services will continue to increase.

Women. The Centers for Disease Control estimates that between 120,000 and 160,000 adult and adolescent women are living with HIV in the United States, and that 44,500 of them have AIDS.⁵ The proportion of new AIDS cases attributed to women tripled from 7% in 1985 to 22% in 1997. Among women reported with AIDS in 1997, 38% were infected through sex with men, 32% were infected through injection drug use, while 28% were of unidentified or unreported risk.⁶ A large proportion of women with AIDS were infected through sex with a male injection drug user.

In 1996 (the most recent year for which complete data are available), HIV/AIDS was the fourth leading cause of death for women ages 25-44, and the leading cause of death among African-American women in this age group. In recent years, new treatments for HIV have helped to reduce the number of AIDS-related deaths among women. However, while AIDS related deaths among men declined by 29.9% from 1995 to 1996, AIDS-related deaths among women only declined by 16.9%.

Women of color are disproportionately affected by HIV/AIDS. Although African-American women and Latinas make up about 21% of the U.S. population, they account for almost 80% of the AIDS cases reported among women in 1997.⁷

Infants and children. By the end of 1997, 8,086 AIDS cases among children had been reported to the CDC. Over 90% of these cases were the result of perinatal HIV transmission - - transmission of HIV from mother to child. Among perinatally infected children with AIDS, 61% are African-American and 24% are Latino.

In 1994, researchers demonstrated that when the drug AZT is given to HIV-infected pregnant women throughout pregnancy and to their newborns for six weeks after delivery, the risk of perinatal HIV transmission can be reduced by nearly 70%. These findings gave new urgency

⁵ Centers for Disease Control and Prevention, *Critical Need to Pay Attention to HIV Prevention for Women: Minority and Young Women Bear Greatest Burden* (Atlanta: CDC: 1998) 1.

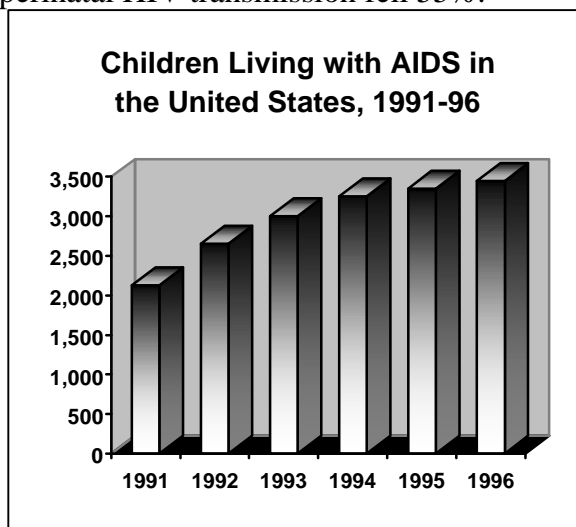
⁶ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 9.2*: 31.

⁷ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 9.2*: 11.

to the need to link pregnant women to comprehensive prenatal care that includes HIV counseling, voluntary testing and access to treatment. Current U.S. Public Health Service (PHS) guidelines call for universal HIV counseling, and voluntary testing with informed consent, of all pregnant women. As required by the Ryan White CARE Act Amendments of 1996, all states have certified that they have implemented these guidelines. The PHS has also issued guidelines recommending the use of AZT in HIV-positive pregnant women and their newborns to help reduce perinatal HIV transmission.

As health care providers have implemented the PHS guidelines, the rate of perinatal HIV transmission in the United States has declined dramatically. Between 1994 and 1997, the number of reported AIDS cases resulting from perinatal HIV transmission fell 55%.^{8,9} Studies also show that the acceptance rate of HIV testing among pregnant women is very high.¹⁰

Some people have wrongly concluded that, as fewer children are born with HIV infection, less funding is needed for pediatric and maternal HIV/AIDS services. In fact, as the death rate among children with AIDS goes down, the number of children living with AIDS in need of services increases (see chart). Second, as the number of HIV-infected women of childbearing age continues to rise, more resources are required



to provide HIV-positive pregnant women with prenatal care, HIV counseling and testing, and access to treatment to improve their health and reduce perinatal HIV transmission.

Youth. HIV is having an increasing impact on adolescents and young adults. It has been estimated that about half of new HIV infections in the U.S. occur in people under age 25, and one quarter occur in people under age 22.¹¹

By the end of 1997, 3,130 adolescents ages 13-19, 22,953 young adults ages 20-24 and 88,415 young adults ages 25-29 had been reported with AIDS. Because of the delay between infection with HIV and the development of AIDS, many - - perhaps most - - of the young adults who develop AIDS in their twenties were infected with HIV as teenagers.

Among men ages 13-24 reported with AIDS in 1997, 51.9% were infected through sex with other men, 10.1% were infected through injection drug use, 6.9% were infected through sex

⁸ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 7.2*: 9.

⁹ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report 9.2*: 13.

¹⁰ Lindsay et al., "Determinants of Acceptance of Routine Voluntary Human Immunodeficiency Virus Testing in an Inner-City Prenatal Population," *Obstetrics and Gynecology* 78 (1991): 678-80.

¹¹ Philip S. Rosenberg et al., "Declining Age at HIV Infection in the United States," *New England Journal of Medicine* 330 (1994): 789.

with women, 4.6% had both sex with men and injection drug use as risk factors, 3.2% had hemophilia, 0.8% were infected through blood transfusions, blood products, or tissue; and 22.5% were of unidentified or unreported risk. Among women ages 13-24 reported with AIDS in 1997, 49.3% were infected with HIV through sex with men, 12.6% were infected through injection drug use, 1.8% were infected through blood transfusions, blood products or tissue, and 36.2% were of unidentified or unreported risk.

Compared to adults over 25, young people ages 13-24 reported with AIDS in 1997 were almost twice as likely to be female (39.9% vs. 21.1%) and were more likely to be infected through heterosexual sex (23.9% vs. 13.1%). African-Americans and Hispanics are disproportionately represented among all adolescent AIDS cases, accounting for 57% of male cases and 83% of female cases.¹²

Young people are less likely to be insured by Medicaid or private insurance than any other age group. This lack of health care access, coupled with a lack of adequate HIV outreach, counseling, and testing programs targeting at-risk youth, have resulted in a large gap between the total number of HIV-infected youth and the number of HIV-infected youth in care. Studies indicate that HIV-infected young people tend to enter care only once they are considerably immunosuppressed or have developed HIV-associated symptoms.¹³ Therefore, a key challenge for adolescent HIV programs is to identify and enroll young people in care.

¹² Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report* 9.2: 10-16.

¹³ Audrey S. Rogers et al., "The REACH Project of the Adolescent Medicine HIV/AIDS Research Network: Design, Methods, and Selected Characteristics of Participants," *Journal of Adolescent Health* 22 (1998): 300-311.

The CARE Act Today

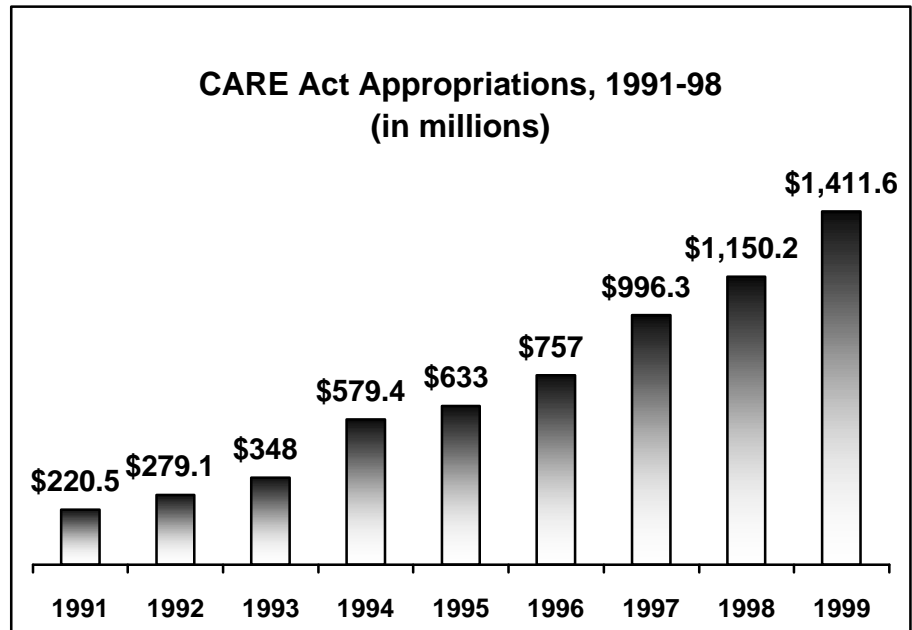
The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is a key federal resource for people living with HIV and AIDS. Congress enacted the CARE Act in 1990 by a nearly unanimous vote to provide emergency disaster relief to help states and communities respond to the AIDS epidemic. Since that time, the CARE Act has enabled communities across the country to develop an infrastructure for delivering quality HIV/AIDS services. In 1995, Congress reauthorized the CARE Act, making a number of significant changes. The reauthorized CARE Act was signed into law in June of 1996.

The CARE Act provides funding for services through several funding streams, known as titles, which direct funds to

cities, states, and community-based programs. Each title targets a different aspect of the service delivery system for people with HIV/AIDS. Programs funded by different titles are required to work together in order to maximize coordination and reduce duplication of services. All Ryan White CARE Act programs are administered by the HIV/AIDS Bureau of the Health Resources and Services Administration of the U.S. Department of Health and Human Services.

Title I of the Ryan White CARE Act provides emergency funding to the eligible metropolitan areas (EMAs) that are most impacted by the HIV epidemic. In order to be designated as an EMA, communities must have reported over 2,000 AIDS cases during the most recent five-year period. EMAs must also have a population of at least 500,000 (this provision does not apply to any EMA funded prior to FY 1997). In FY 1998, 49 EMAs received Title I funding; in FY 1999, two additional cities will become EMAs. Approximately three-quarters of people with AIDS in the United States live in an EMA.

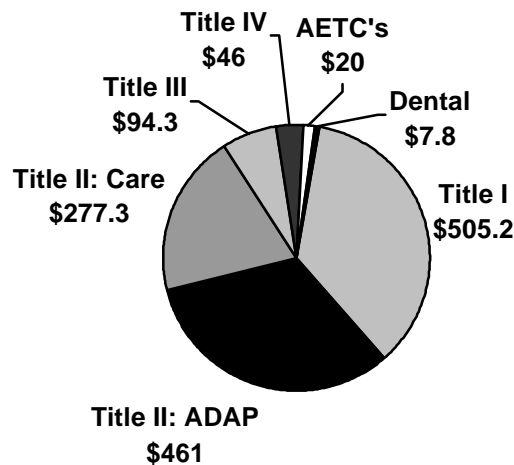
EMAs are eligible to receive both formula and supplemental funding through Title I. Formula funding is based on the estimated number of people living with AIDS in each EMA. The CARE Act provides that no EMA will receive less than a certain percentage of its FY 1995 award; for example, in FY 1998, no EMA received less than 98% of its FY 1995 award. Title I supplemental funding is awarded on a competitive basis to EMAs that demonstrate the most severe need.



EMAs may use Title I funds to help pay for a variety of services, including primary medical care, home health and hospice care, dental services, case management, mental health care, housing and transportation assistance, nutrition services, and day/respite care. Each EMA funds services according to priorities set by a local HIV planning council, which must include public health professionals, health care providers, and people living with HIV. Planning councils are also required to include a representative from a Title IV program, or if there is no Title IV program operating in the area, representatives of organizations with a history of serving children, youth and families living with HIV.

Title II of the CARE Act provides funds to all states, the District of Columbia, Puerto Rico, and U.S. territories to improve the quality, availability and organization of care services for people living with HIV. Typically, Title II grants are administered by state health departments. Title II is designed to assure that all people living with HIV have access to adequate HIV care, regardless of whether they live in rural, suburban, or urban areas.

**CARE Act Fiscal Year 1999 Appropriations
(in millions)**



Each state receives Title II formula funding based on two key factors: the estimated number of people living with AIDS in the state as a whole, and the estimated number of people living with AIDS in the state outside of Title I EMAs. All states receive a minimum of \$100,000 from Title II, regardless of their estimated number of people living with AIDS. States that account for more than one percent of the total U.S. AIDS cases reported during the previous two years must match a certain percentage of Title II funds with state funds, based on a formula in the CARE Act.

States may direct Title II funds toward a range of health care and support services, including primary medical care, home health and hospice care, dental services, case management, mental health services, transportation assistance, nutrition services, and day/respite care. In most states, a portion of Title II funds are used to support local and/or regional consortia, which are associations of HIV service providers that plan, develop and deliver services for people with HIV. Title II funds may also be used to pay for health insurance continuation programs, which enable people with HIV to continue their private health insurance coverage if they can no longer afford their premiums. Through the AIDS Drug Assistance Program

(ADAP), Title II helps people with HIV who are uninsured or underinsured to pay for HIV-related medications. ADAP has enabled many people with HIV to afford the powerful, but expensive, HIV treatments that have become available in recent years.

Title III provides grants to public and private community-based clinics to provide outpatient health services for people with HIV. Title III grantees include community and migrant health centers, hospital and university-based medical centers, and city and county health services. Many of these programs target historically underserved and/or geographically remote communities. In 1996, 153 Title III programs provided primary health care services to more than 84,000 people with HIV.¹⁴

Title III funds may be used for numerous activities, including HIV counseling and testing, primary medical care, pharmaceuticals, dental services, case management, mental health care, nutrition services, and treatment of tuberculosis and substance abuse.

Title IV provides competitive grants to public and private nonprofit entities to develop and sustain comprehensive, coordinated systems of HIV care and services for children, youth, women and families. Title IV funds may be used to provide a variety of services, including primary medical care, social services such as case management, and access to research.

History. Although Congress first authorized the Ryan White CARE Act in 1990, the Title IV program was not funded until FY 1994. That year, community programs that had previously been funded through the federal Pediatric and Family AIDS Demonstration program were moved into Title IV.

When the CARE Act was reauthorized in 1996, Congress made a number of important changes to Title IV. For example, the reauthorized CARE Act broadened the mandate of Title IV to serve infants, children, youth, women, and families. The CARE Act conference committee further clarified in report language that the purpose of Title IV is to fund "programs that provide or arrange for innovative comprehensive HIV care for children, youth, women and families with or affected by HIV." In addition, the 1996 CARE Act contains provisions that require grantees to facilitate client access to HIV clinical research. Specifically, programs are required to identify women, infants, children, and youth who may be "appropriate participants" in HIV clinical research, and to enroll a "significant number" of these patients into research protocols.

In FY 1998, Title IV funded 48 grantees in 27 states, the District of Columbia and Puerto Rico. These grantees provide and/or arrange for direct HIV services at several hundred clinical sites. Title IV grant amounts range from \$242,000 to \$2 million.

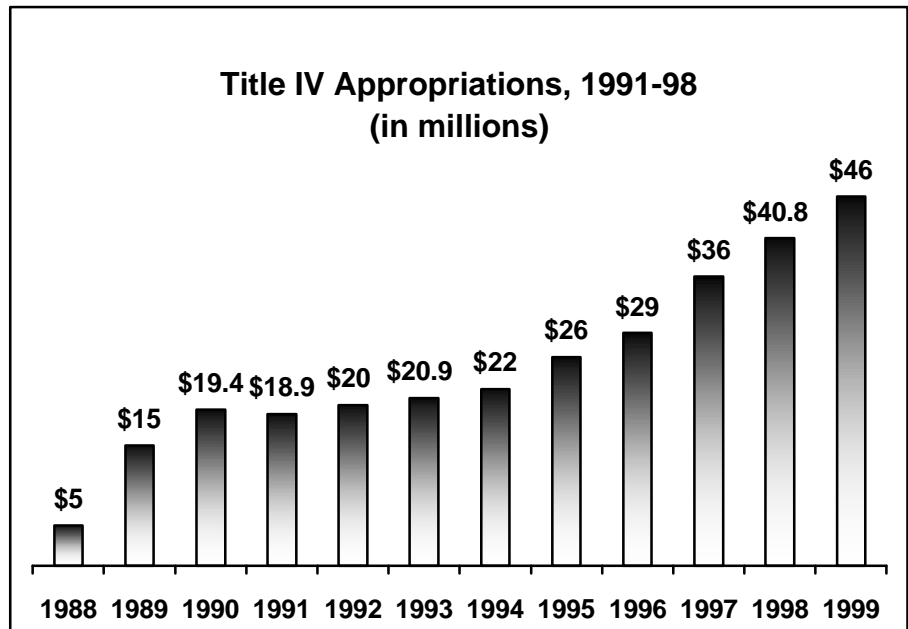
Title IV and Women, Children, and Youth. In 1996, the most recent year for which data are available, the Ryan White Title IV program served 34,614 people living with and at risk for

¹⁴ Health Resources and Services Administration, *1996 Early Intervention Services Narrative Report (summary)*, 1998.

HIV. Among clients, 24.1% were adult women, 10% were adolescent or adult pregnant women, and 8.1% were adult men. Thirteen percent of clients were infants, 26.8% were children, and 17% were adolescents or young adults. The number of clients served by Title IV increased more than 50% from 1995 to 1996, a result of additional Title IV projects and increased demand for services.¹⁵

Women and infants. HIV testing and prenatal care programs supported by Title IV have helped to dramatically reduce the rate of perinatal HIV transmission in the United States. Title IV programs are increasingly enrolling women during pregnancy rather than after they have given birth, enabling health care providers to reduce the rate of HIV transmission from mothers to infants.

In collaboration with the Special Projects of National Significance Program, Title IV funds the Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission. This initiative, known as WIN, provides funding to seven community-based projects to improve care for HIV-positive women and to reduce rates of perinatal HIV transmission. WIN sites provide outreach, counseling, and testing to women of childbearing age, health care to pregnant women and their children, broad-based community education to women about HIV, and education to health care and social service providers about reducing perinatal transmission. During 1996, WIN project sites provided HIV



outreach and/or counseling to over 12,000 women and provided health care to more than 600 HIV-positive women and over 700 infants.

Youth. In recent years, Title IV programs have increasingly served HIV positive young people. Between 1995 and 1996, the number of adolescents and young adult clients reported by Title IV programs more than doubled. Title IV programs have been particularly successful at reaching young women, one of the fastest-growing HIV risk groups in the nation. In 1996, 73% of adolescent and young adult clients were young women.

¹⁵ Health Resources and Services Administration, *Ryan White Title IV Grant Program Summary Presentation and Comparisons of Selected 1995 and 1996 Data Element (sic) Reported by Grantees*, June 1998.

In collaboration with the National Institutes of Health, the Title IV program has established the REACH Project, a research program that is studying the medical, psychosocial, and behavioral aspects of HIV in adolescents. With approximately 350 teens enrolled at 15 sites across the country, the REACH Project is the source of much of what is known about HIV disease in adolescents.

In September 1998, Title IV launched a new Title IV Adolescent Initiative, which was established to increase the number of HIV positive youth aged 13-24 receiving primary medical care and support services in a youth sensitive environment. This \$2 million dollar program currently funds model youth programs in five locations: New Orleans, Boston, San Francisco, Chicago, and Rio Piedras, Puerto Rico.

Title IV and People of Color. Title IV serves a higher proportion of people of color than any other program of the Ryan White CARE Act. In 1996, 48% of clients served by Ryan White Title IV programs were African-American; 30.4% were Hispanic, 12% were Caucasian, and 1.6% were Asian-American. The remaining 7.8% of clients were of other or unknown race. The number of African-American clients reported by Title IV projects increased by nearly 50% from 1995 to 1996. The number of Hispanic and Asian-American clients served by Title IV has also steadily increased.¹⁶

Part F of the CARE Act (often referred to as "Title V") authorizes three separate programs:

- The **HIV/AIDS Dental Reimbursement Program** provides partial reimbursement to dental schools and post-doctoral dental programs that provide oral health care to uninsured and/or indigent people with HIV. In 1997, the Dental Reimbursement Program served approximately 70,000 people at over 100 dental education institutions.
- The **AIDS Education and Training Center (AETC) Program** is a network of 15 centers throughout the United States that conduct multidisciplinary education and training programs for health care providers. The AETC program helps to ensure that health care and social service providers, including those in rural areas, have the necessary skills and knowledge to provide state-of-the-art HIV care. More than 700,000 providers have been trained by AETCs since 1991.¹⁷
- The **Special Projects of National Significance (SPNS) Program** provides competitive grants to support the development and evaluation of innovative and replicable models of HIV care and services. SPNS receives a percentage of the appropriated funds for Titles I, II, III, and IV, at a maximum of \$25 million. SPNS projects have targeted a variety of traditionally underserved populations, including adolescents, incarcerated individuals, residents of rural areas, and Native Americans.

¹⁶ Ibid.

¹⁷ Health Resources and Services Administration, "HIV/AIDS Bureau," (fact sheet) June 1998.

Other Key Provisions of the CARE Act

- **Statewide Coordinated Statement of Need.** The CARE Act requires that programs funded by the CARE Act in each state jointly develop a document called the Statewide Coordinated Statement of Need. This process is intended to facilitate communication and collaboration, and to reduce unnecessary duplication of services.
- **Percentage of funds for infants, children, and women.** The CARE Act requires that EMAs spend Title I funds in accordance with the local demographics of AIDS, including proportionate allocations for infants, children, and women living with AIDS. Likewise, states must show that Title II funds are being spent proportionately on infants, children, and women.

Renewing the Ryan White CARE Act: Summary of a Panel Discussion

AIDS Alliance's fourth annual conference, *Voices '98*, included a panel discussion titled, "New Hope, New Options, New Needs: Renewing the Ryan White CARE Act in 2000." The session was facilitated by Dorothy Mann, Executive Director of the Family Planning Council of Southeastern Pennsylvania and chair of AIDS Alliance's Government Affairs Committee. Panelists included consumers and providers of services funded by various titles of the CARE Act, local and national AIDS advocates, and a representative from the HIV/AIDS Bureau of the Health Resources and Services Administration.

Following are the questions that were posed to the panel and a synopsis of responses. The comments do not necessarily represent the views of all of the panelists, of AIDS Alliance, or of the Children Affected by AIDS Foundation.

1. What lessons were learned during the last reauthorization of the Ryan White CARE Act?

Not all of the panelists were actively involved in the last reauthorization of the CARE Act, which began in 1994 and concluded in 1996. Those panelists who were involved made the following points:

- *Build a unified coalition.* During the last reauthorization process, conflicts arose among advocates and organizations that threatened the political effectiveness of the AIDS community as a whole. It is essential for stakeholders in the CARE Act to come to consensus on as many issues as possible and establish a strong grassroots coalition. Building consensus is not always easy: it requires bringing people and groups with diverse experiences and perspectives together, working out difficult issues, and making compromises to move forward as a unified force.
- *Start early.* Gathering input from people with HIV, service providers and advocates across the country about reauthorization of the CARE Act will take time. It will also take

time to build trust and cooperation among the many diverse communities that will be involved. To maximize our political clout, AIDS advocates must work out our differences *before* Congress begins the reauthorization process.

- *Identify priorities.* Like most federal legislation, the CARE Act will never be perfect. During the last reauthorization process, AIDS Alliance secured legislative changes that resulted in significant gains for children, youth, women, and families. However, we did not get all of the changes we wanted, and some provisions that we opposed ended up in the final law. The key will be to identify and achieve our top legislative priorities, and to recognize when compromises are appropriate.

2. How well is the CARE Act responding to the needs of children, youth, women and families living with and affected by HIV/AIDS?

- Panelists agreed that the Ryan White CARE Act has made a tremendous difference in the lives of children, youth, women, and families living with and affected by HIV/AIDS. The CARE Act has filled service gaps and provided a safety net for hundreds of thousands of people with HIV in resource-poor communities.
- The Ryan White Title IV program has successfully responded to the unique service needs of children, youth, women, and families. Title IV projects have developed family- and youth-centered, community-based programs that address key barriers to medical care faced by traditionally underserved populations. Title IV projects have also facilitated client access to HIV clinical research opportunities, such as clinical trials. As a competitive grant program, Title IV has targeted federal funds directly to communities in greatest need and to providers that are well-qualified to serve children, youth, women, and families.
- Title I funds are spent by EMAs according to priorities set by local planning councils, and many states administer Title II funds through local consortia. The CARE Act requires that the membership of planning councils reflect "the demographics of the epidemic" in the EMA, "with particular consideration given to disproportionately affected and historically underserved groups and subpopulations." However, in some communities, young people, women and families do not have a substantial role in Title I and II planning processes. As a result, funding priorities may not adequately reflect the priorities of children, youth, women, and/or families affected by HIV.
- The CARE Act requires that EMAs spend Title I funds in accordance with the local demographics of AIDS, including proportionate allocations for infants, children, and women living with AIDS. Likewise, states must show that Title II funds are being spent proportionately on infants, children, and women. States are also required to demonstrate that consortia "meet the special needs of families with HIV disease, including family-centered and youth-centered care." Some panelists expressed the opinion that many

EMAs and states are not meeting these legislative requirements, or simply provide a certification on an aggregate level that the proportional allocation requirement is being met. Panelists pointed out that aggregate allocations do not necessarily result in funding for specific services that reflect the priorities of women and families.

- Title IV programs provide "family-centered care," which means that care and services are built around the needs of whole families affected by HIV. For example, a case manager funded by Title IV might coordinate services for a family of three that includes an HIV-positive mother, an HIV-positive child and an HIV-negative child. In contrast, Title I and II funds may not be used to serve HIV-negative individuals, according to regulations issued by the Health Resources and Services Administration. This requirement may be an impediment to using Title I or II funds to expand support for family-centered care.
- Panelists agreed that the reauthorized CARE Act must better meet the needs of HIV-positive young people. In general, youth have not been well targeted by CARE Act programs. In 1996, adolescents ages 13 to 19 accounted for 4.1% of Title I clients, 2% of Title II (non-ADAP) clients, 0.5% of ADAP clients, and 0.9% of Title III clients.^{18,19} The Title IV program served a significantly higher proportion of 13- to 19-year-olds in 1996, with 11.1% of clients.²⁰ Title IV's Adolescent Initiative is now the only ongoing federal CARE Act program that is dedicated to youth.

3. The HIV epidemic has changed a lot since the CARE Act was reauthorized. More women, youth and people of color are living with HIV. How can the CARE Act better serve people living with HIV and what changes may need to be considered?

- *More data are needed.* Most panelists agreed that more information is needed before we decide how the CARE Act should be changed in the year 2000. There are a number of potential ways to determine how well the CARE Act is serving children, youth, women and families, and how it could be improved. HRSA is currently developing an outcome-oriented data collection system for CARE Act programs. This new data system will expand the scope of data collection to capture the medical, psychosocial, and other outcomes associated with CARE Act services. Once the system is implemented, the results should help identify opportunities to improve CARE programs. Unfortunately, data from this new system will not be available until after the CARE Act is reauthorized. Alternative methods to assess the effectiveness of the current CARE Act and identify future needs include further analysis of currently available data, evaluation of a

¹⁸ Health Resources and Services Administration, *Ryan White CARE Act, Title I and II Annual Administrative Report (AAR) 1996 National Data Tables*, May 1998.

¹⁹ Health Resources and Services Administration, *1996 Early Intervention Services Narrative Report (summary)*, 1998.

²⁰ Health Resources and Services Administration, *Ryan White Title IV Grant Program Summary Presentation and Comparisons of Selected 1995 and 1996 Data Element (sic) Reported by Grantees*, June 1998.

representative sample of programs funded by the CARE Act, and client surveys and focus groups.

- *Alter the research requirement of Title IV.* There is broad agreement that Title IV programs play a very important role in facilitating voluntary access to research opportunities, and that access to research is an important aspect of comprehensive HIV care. However, several panelists and audience members spoke out against the current legislative requirement that Title IV programs enroll a "significant number" of clients into HIV clinical research. Speakers noted several concerns about this requirement, one of which is that it may create an improper incentive for health care providers to encourage their clients to enroll in experimental research protocols.
- *Strengthen support for youth programs.* It was suggested that the reauthorized CARE Act should continue and expand the Title IV Adolescent Services Initiative, so that more communities can receive funding for comprehensive youth programs.

4. Given that the Ryan White CARE Act legislation is the result of a political process in Congress, and that the White House will develop its own recommendations for reauthorization, what are the factors that will influence the bill in 2000 and how should the community prepare?

Panelists noted a number of current policy issues that may influence the reauthorization process, including the following:

- *1998 Congressional elections.* The 1998 Congressional elections will have major implications for CARE Act reauthorization. The House Commerce Committee and the Senate Labor and Human Resources Committee - - the two committees with jurisdiction over the CARE Act - - are likely have new members who will need to be educated about the CARE Act and other AIDS programs. With some key Congressional members and staff from the last CARE Act reauthorization now gone, the AIDS community may need to look for new allies.
- *Perception that the HIV epidemic is over.* Excitement over new therapies for HIV has given some people, including policymakers, the impression that the HIV/AIDS crisis is over. Some are asking questions about whether HIV/AIDS is still an "emergency." It will be crucial for the AIDS community to help the public and policymakers understand that the new HIV drugs do not work for everyone, especially in the long term. Also, as more people are infected with HIV and less people die from the disease, more people will require HIV care and services. Although the demand for hospitalization and hospice care has declined, basic HIV care has become far more complex than ever before. Thus, the overall cost of care for people with HIV may actually increase.
- *Perception that the pediatric HIV epidemic is over.* As the rate of perinatal HIV transmission continues to decline, some policymakers may conclude that federal funds

for pediatric HIV care and research are less needed. Panelists noted the importance of educating Congress that resources are still needed to further reduce the rate of perinatal HIV transmission, systems of care must be maintained for children who are born with HIV infection, and more children than ever before are living with AIDS and require care and services. In addition, an increasing number of HIV-negative children are being born to HIV-positive mothers, and require specialized care and support.

- *Medicaid expansion.* A top priority for AIDS advocates in recent years has been to extend Medicaid eligibility to low-income persons who are HIV-positive but have not developed symptomatic HIV disease. This effort appears to be gaining momentum: in August 1998, 68 members of the U.S. House of Representatives sent a letter urging Donna Shalala, Secretary of the Department of Health and Human Services, to exercise her authority to expand Medicaid coverage. If the push to expand Medicaid is successful, it would provide a means of payment for some services that are currently funded by the CARE Act. However, the experience of the Title IV program indicates that the Ryan White CARE Act would still be needed. Many Title IV clients are covered by Medicaid, most of them women and children. Yet Medicaid does not fully cover the costs of medical care, nor does it cover many critically needed support services. In addition, even if Medicaid is expanded, income requirements would still exclude many uninsured and underinsured people with HIV from coverage.
- *HIV surveillance.* Currently, all U.S. states keep track of AIDS cases through disease surveillance, but only about half of the states track HIV cases. As fewer people with HIV progress to an AIDS diagnosis, the Centers for Disease Control is expected to encourage all states to expand their AIDS surveillance systems to include HIV reporting. This shift is likely to have an important impact on the CARE Act. Many people anticipate that, when the CARE Act is reauthorized, Congress will change the Title I and II funding formulas to take HIV cases into account. If this happens, it is not known what would happen to states that do not implement HIV surveillance.

5. How can people with AIDS, service providers, and advocates get involved in the reauthorization process?

Panelists offered many ideas about how people can get involved with the reauthorization process, including the following:

- *Get involved at the local level.* Consider participating in meetings of your local planning council or consortium. This is a good way to learn more about how the CARE Act affects your community. If you do not have time to attend regular meetings, there may be other opportunities to get involved, such as participating in a town hall meeting. Also look into getting involved with a local AIDS advocacy organization.

- *Learn more about the CARE Act.* More information about the CARE Act is available from a variety of sources. The resource list at the end of this document includes a number of national organizations that can provide additional information.
- *Attend Voices '99.* AIDS Alliance's 5th annual conference, *Voices '99*, is scheduled for May 22-25, 1999, in Washington D.C. *Voices '99* is the only national conference to focus on HIV issues affecting children, youth, women, and families. The conference will include several sessions devoted to reauthorization of the CARE Act.
- *Participate in public meetings about CARE Act reauthorization.* A number of local, regional and national public meetings focused on CARE Act reauthorization will take place over the next two years. For example, the HRSA AIDS Advisory Committee has already begun to hold regional public hearings about reauthorization of the CARE Act. At some meetings, you will have an opportunity to tell policymakers about your experience with the CARE Act and how the legislation could be improved. Contact AIDS Alliance for more information.

**National Organizations Representing
Ryan White CARE Act Programs:**

Titles I and III:

Cities Advocating for Emergency AIDS
Relief (CAEAR) Coalition
1413 K Street NW, Suite 700
Washington, D.C. 20005
(202) 789-3565 / Fax: (202) 789-4277
E-mail: caearindc@aol.com

Title II:

National Alliance of State and Territorial
AIDS Directors
444 North Capitol Street NW
Suite 339
Washington, DC 20009
(202) 434-8090 / Fax: (202) 434-8092
Web page: www.nastad.org
E-mail: NASTAD@nastad.org

ADAP (AIDS Drug Assistance Program)
Working Group
1775 T Street NW
Washington, DC 20009
(202) 588-1775 / Fax: (202) 588-8868
E-mail: ADAP_WG@aol.com

Title II Community AIDS National Network
1775 T Street NW
Washington, DC 20009
(202) 588-1775 / Fax: (202) 588-8868
Web page: www.t2cann.org
E-mail: webmaster@t2cann.org

Title IV:

AIDS Alliance for Children, Youth &
Families
1600 K Street NW, Suite 201
Washington, DC 20006
(202) 785-3564 / Fax: (202) 785-3579
Web page: www.aidspolicycenter.org
Email: info@aidspolicycenter.org

AIDS Education and Training Centers:

AIDS Action
1906 Sunderland Place NW
Washington, DC 20036
(202) 530-8030 / Fax: (202) 530-8031
Web page: www.aidsaction.org
E-mail: aidsaction@aidaction.org

Additional Resources:

Children Affected by AIDS Foundation
6033 W. Century Boulevard, Suite 260
Los Angeles, CA 90045
(310) 258-0850 / Fax: (310) 258-0851

White House Office of
National AIDS Policy
736 Jackson Place
Washington, DC 20503
(202) 456-2437 / Fax: (202) 456-2438

HIV/AIDS Bureau Office of
Communications
Health Resources and Services
Administration (HRSA)
5600 Fishers Lane, Room 7-46
Rockville, Maryland 20857
(301) 443-6652 / Fax: (301) 443-0791
Web page: www.hrsa.dhhs.gov/hab/

National Association of People With AIDS
1413 K Street NW, 7th Floor
Washington, DC 20005
(202) 898-0414 / Fax: (202) 898-0435
Web page: www.napwa.org
Email: napwa@napwa.org

National Minority AIDS Council
1931 13th Street NW
Washington, DC 20009-4432
(202) 483-6622 / Fax: (202) 483-1135
Web page: www.nmac.org
E-mail: jyoshida@nmac.org

Ryan White CARE Act Reauthorization Timeline

1999

January	106th Congress, first session convenes
February	President Clinton's final budget due for Fiscal Year (FY) 2000
April	Proposed House hearings on the "state of AIDS"
September 30	FY 1999 ends
October 1	FY 2000 begins

2000

September 30	FY 2000 ends; Ryan White CARE Act authorization expires
October 1	FY 2001 begins
November	Presidential and Congressional elections

2001

January	Presidential inauguration; 107th Congress convenes
September 30	FY 2001 ends