

## Renewing the Commitment

The 2005 Reauthorization of the Ryan White CARE Act



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AIDS Alliance for Children, Youth & Families

Policy Position Paper

March 2005

<b>Foreword .....</b>	<b>1</b>
<b>Introduction .....</b>	<b>2</b>
About the Ryan White CARE Act.....	2
About AIDS Alliance.....	3
Our Stake in Reauthorization .....	3
<b>Women, Children, Youth, and Families Affected by HIV/AIDS .....</b>	<b>5</b>
Epidemiological Profile .....	5
Special Needs of Women, Children, Youth, and Families.....	6
Preventing Mother-to-Child Transmission of HIV (MTCT): The Role of Voluntary Testing and Comprehensive Services.....	8
<b>The Ryan White CARE Act Today.....</b>	<b>10</b>
Four Titles and Other Programs: The Structure of the CARE Act .....	10
Women, Infants, Children and Youth (WICY) Set-Asides.....	11
<b>Title IV: The Unique Structure and Benefits of Family-Centered Care .....</b>	<b>12</b>
About Title IV Grantees .....	12
Family-Centered Approaches to Care.....	13
<b>Reauthorizing the Ryan White CARE Act in 2005: Policy Principles from AIDS Alliance ....</b>	<b>14</b>
Defining Our Policy Priorities.....	14
Ten Policy Principles and Justifications .....	15
Existing Legislation.....	23

## Foreword

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Since 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has played a principal role in providing care and treatment for people affected by HIV/AIDS. More than 500,000 Americans depend on it to meet their needs for medical care, treatment, and support services. Through CARE Act services, we have drastically reduced HIV/AIDS-related illness and death, and nearly eliminated mother-to-child transmission in the United States.

In September 2005, the CARE Act will expire, and Congress is taking up the issue of reauthorizing, or renewing, this important legislation. The Administration and Congressional leaders of both parties have already begun this process, and we hope to see a speedy enactment in the coming months.

Recently, much needed attention in the public policy arena has been paid to the impact HIV/AIDS is having around the world. The document's title, *Renewing the Commitment*, is meant to remind us that in addition to the devastation wrought abroad, HIV/AIDS remains a crisis here at home, and that we still need a robust response from the federal government to help save lives, keep people healthier, and prevent new infections. This document offers principles on how the CARE Act should be reauthorized to best serve women, children, youth, and families affected by HIV/AIDS.

*Renewing the Commitment* reflects the hard work of many individuals. Thanks to Dorothy Mann and the members of the Government Affairs Committee of the board for their efforts in developing our reauthorization principles, and reviewing and editing this document. Thanks also to the staff members who coordinated the writing, editing, and production of this paper: Mark Del Monte, Michael Stevens, Mary McGonigel, and Ann Checkley.

We hope this document informs the debate as Congress and the Administration take up CARE Act reauthorization. Women, children, youth, and families affected by HIV/AIDS depend upon their actions, and developing effective public policy is crucial to providing quality care and treatment to all who need it.

Ivy Turnbull  
President

David C. Harvey  
Executive Director

## Introduction

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### *About the Ryan White CARE Act*

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is the largest federal discretionary program dedicated to providing care and treatment to people living with HIV/AIDS. Reaching more than 533,000 people annually, the CARE Act provides a lifeline for people living with HIV/AIDS by saving lives and improving quality of life. The CARE Act provides medical care, pharmaceuticals, and a variety of support services such as childcare, transportation, housing, mental health services, and case management. The CARE Act has been greatly successful in reducing HIV/AIDS morbidity and mortality and is an integral part of the service structure for people living with HIV/AIDS.

First enacted in 1990 and reauthorized in 1996 and 2000, CARE Act programs provide services to people living with HIV/AIDS who are uninsured or underinsured. By law, the CARE Act is a payer of last resort, thereby maximally leveraging other public and private resources in the provision of health care to low-income people with HIV/AIDS.

Consumers who receive CARE Act services tend to be poorer than other HIV-positive people who do not use the program, and in some programs under the CARE Act, more than 70 percent of clients live below the federal poverty level.<sup>1</sup> More than 50 percent of CARE Act consumers have annual incomes below \$25,000.<sup>2</sup> Because the CARE Act serves as the payer of last resort, it fills critical service gaps left un-funded by Medicaid, Medicare or private insurance.

The CARE Act expires on Sep. 30, 2005, and broad support exists for its reauthorization. President Bush has publicly called for the law's renewal, and congressional leaders of both parties are actively engaged in developing policy and legislative proposals to reauthorize the CARE Act on time. The Ryan White CARE Act has always enjoyed broad bipartisan support. Its original sponsors were Senators Edward M. Kennedy (D-Mass.) and Orrin Hatch (R-Utah). The CARE Act has been passed and reauthorized with vote totals of 95-4 and 97-3 in the Senate, and 408-14, 402-4, and 411-0 in the House.

AIDS Alliance for Children, Youth & Families supports speedy CARE Act reauthorization and looks forward to working with the Congress and Administration on this important legislation.

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<sup>1</sup> Health Resources and Services Administration, "The AIDS Epidemic and the Ryan White CARE Act: Past Progress, Future Challenges," 2003.

<sup>2</sup> Health Resources and Services Administration fact sheet, "Ryan White CARE Act: CARE Act Overview" July 2002.

## *About AIDS Alliance*

AIDS Alliance for Children, Youth & Families is the only national non-profit organization dedicated solely to women, children, youth, and families affected by and at risk for HIV/AIDS. Based in Washington, D.C., AIDS Alliance is a national training, education, and advocacy organization. Our provider members include over 650 community-based organizations that serve more than 53,000 women, children, youth, and families affected by HIV/AIDS each year. Many of our members are funded under Title IV of the Ryan White CARE Act.

Since our founding in 1994, AIDS Alliance's board of directors and members have been at the forefront of providing comprehensive, family-centered care to women, male caregivers, children, and youth affected by HIV/AIDS. Indeed, even before Title IV was established in the 1996 reauthorization of the CARE Act, our members were national leaders in developing care models to reach these constituencies and provided guidance to HRSA and Congress on the development of the Title IV program. AIDS Alliance was active in both the 1996 and 2000 reauthorizations of the CARE Act and is well-suited to provide expertise on policy related to Title IV and other CARE Act issues affecting women, children, youth, and families affected by HIV/AIDS.

## *Our Stake in Reauthorization*

The Ryan White CARE Act has been enormously successful in meeting its mission to provide life-extending care and services. Because of advancements in care and treatment, the death rate from AIDS has been reduced by as much as 80 percent, and many years are being added to life expectancy for people living with HIV/AIDS.<sup>3</sup>

For many low-income people with HIV/AIDS these crucial services can only be accessed through the Ryan White CARE Act. If individuals have assets above the state's eligibility level for Medicaid, and are not yet eligible due to disability status, then they may find themselves without private health insurance and without Medicaid. Further, even if they do have public or private insurance, frequently the costs of medical care, anti-AIDS medications, and necessary support services exceed insurance coverage or are not reimbursable. These individuals desperately need continued access to medical and support services – their very lives depend on it.

Though we have made significant progress in decreasing HIV-related morbidity and mortality, much more work remains to be done. Poverty, unequal access to care, stigma, and discrimination have prevented women and people of color with HIV/AIDS from achieving the same reductions in illness and death as have other populations<sup>4</sup>. Further, both women and people of color have been underrepresented in clinical trials of anti-AIDS drugs, so drug efficacy and side effects specific to

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<sup>3</sup> International Association of Physicians in AIDS Care, "HAART Slashed AIDS Deaths by 80 Percent." *IAPAC Monthly*, Nov 2003, p. 279.

<sup>4</sup> Health Resources and Services Administration fact sheets, "African Americans and HIV/AIDS," "Women and HIV/AIDS," and "Hispanics and HIV/AIDS," July 2002.

these populations may not be as well understood. The people at the intersection of these two communities – women of color – have been especially disproportionately affected by HIV/AIDS.

Solving these problems is the mission of Title IV programs. By developing medical care and support services especially designed to reach women, children, youth, and families, Title IV grantees have been very successful in bringing these communities affected by HIV/AIDS into care and responding to health care disparities. The vast majority of Title IV consumers are women, and Title IV serves the largest percentage of people of color of any title in the CARE Act. Title IV is working to promote positive health outcomes among women and people of color affected by HIV/AIDS by developing a comprehensive system of care specifically tailored to the needs of these communities, including support and assistance for clinical trial enrollment.

These systems of care require additional support. The CARE Act must be reauthorized on time and with policies that promote effective care and treatment. The reauthorization must acknowledge the difficulty of developing a care network and providing the comprehensive services women, children, youth, and families need. Care and treatment for people living with HIV/AIDS are becoming more complicated. Finding the right treatment regimen is a complex process, and drug resistance and treatment failure can occur over time. Furthermore, though significantly extending people's lives has been a great accomplishment, it has also required addressing other health problems that can arise, independent of HIV infection. Ensuring that all people affected by HIV/AIDS share in the gains made so far in fighting the disease and expanding services to further reduce HIV-related illness, suffering, and death must be the goal of the 2005 reauthorization of the Ryan White CARE Act.

## Women, Children, Youth and Families Affected by HIV/AIDS

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### *Epidemiological Profile*

For more than two decades, HIV/AIDS has been one of the nation's most pressing public health problems. By the end of 2003, more than 929,000 Americans have been diagnosed with AIDS, and more than 524,000 had died. The Centers for Disease Control and Prevention (CDC) estimates that at least 569,000 Americans are living with HIV/AIDS and at least 40,000 new infections occur annually.<sup>5</sup>

HIV/AIDS has had a disproportionate impact on the communities served by Title IV projects: youth, women – especially women of color – and their children and families. Though African American and Latina women make up just 27 percent of the female population, in 2003 they represented 83 percent of new AIDS diagnoses among women. And though for the overall population HIV/AIDS has not been among the fifteen leading causes of death since 1997, it was the number one cause of death for African American women ages 25-34 in 2001.<sup>6</sup> The AIDS rate among Latinos is nearly four times that among Whites; among African Americans it is more than ten times greater. Among women, the disparities are even more shocking: the AIDS rate among African American women is 25 times higher than among white women.<sup>7</sup>

Youth and young adults also continue to be at risk. The CDC estimates that half of the 40,000 annual infections in the U.S. occur among people under the age of 25. In 2002, teen girls represented fully half of HIV cases reported among 13-19 year olds. African American and Latino youth are disproportionately affected, representing respectively 65 percent and 20 percent of AIDS cases reported among 13-19 year olds.<sup>8</sup> Young gay and bisexual men are severely affected by HIV/AIDS. Male-to-male sexual contact remains the top mode of transmission in the United States, and young gay and bisexual men of color are at significantly greater risk of HIV infection than their white counterparts.<sup>9</sup>

By the end of 2003, 9,149 AIDS cases among children under the age of 13 had been reported to the CDC.<sup>10</sup> The great majority of these children are African American and Latino, and most were infected perinatally. HIV incidence among children has decreased dramatically, thanks to the discovery of medical protocols that decrease mother-to-child transmission, paired with the programs that provide such services. These systems have recruited HIV-positive pregnant women into care, helped retain them in care, and promote treatment adherence. Also because of medical advancement and care provision, children with HIV are living longer, healthier lives.

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<sup>5</sup> Centers for Disease Control and Prevention, "HIV/AIDS Surveillance Report." Vol. 15; 2004.

<sup>6</sup> Centers for Disease Control and Prevention, "Deaths: Final Data for 2002," National Vital Statistics Report 53.5 (October 2004); Kaiser Family Foundation fact sheet, "African Americans and HIV/AIDS," February 2005.

<sup>7</sup> Kaiser, *Ibid.*

<sup>8</sup> Kaiser, *Ibid.*

<sup>9</sup> CDC Surveillance Report, *op. cit.*

<sup>10</sup> *Ibid.*

Reauthorization of the CARE Act is taking place in the midst of a changing epidemic. Increasingly, the epidemic is moving toward women, youth, and people of color, and Title IV is responding to the evolving demographics and care needs. Public policy should recognize that HIV/AIDS is a disease that affects not only infected individuals but also their entire families. This is especially true for women of color who have children. Health and medical care for these women takes place in a context that typically includes poverty, the demands of child rearing – often as a single parent – a history of poor access to care, racism, and sexism. Further, as caseloads have increased, flat funding has meant a decrease in the amount of money available to provide care to people living with HIV/AIDS. Recognizing these problems is critical to supporting effective responses to the epidemic.

### *Special Needs of Women, Children, Youth, and Families*

All people living with HIV/AIDS have multiple and complex needs that require specialized health care and support services. This is especially true for women, children, and youth. Finding the right treatment regimens and administering anti-AIDS drugs are complicated and time-consuming for care providers, and individuals typically experience a host of side effects that may affect every aspect of their lives, from their work schedule and ability to leave home, to the foods they can eat and how close they must be to a bathroom at all times. In addition, managing disclosure and stigma with a disease that is still widely misunderstood can create enormous stress on individuals whose immune systems are already compromised. Finally, those populations most at-risk for HIV infection may already be struggling with any combination of poverty, discrimination, substance abuse and unstable housing.

Parents with HIV/AIDS who have children – whether or not the children also have HIV – face enormous challenges. Managing treatment of their own infection while also providing for their children can be extremely difficult, especially if HIV disease has incapacitated them. Coordinating transportation, childcare, and meeting their own medical and social service appointments is especially hard. If a parent is single or has a sick partner, the burden mounts. And when a child or children are also HIV-positive, parents frequently sacrifice their own health care needs to attend to the needs of their children. Parents with HIV/AIDS also must make arrangements for custody and guardianship with much more urgency and a much greater likelihood that those arrangements will be needed than other parents. Most often, these burdens fall on the mother, and, therefore, women's care tends to be affected by these concerns more than men's.

Children with HIV/AIDS face challenges ranging from disclosure at school to their own sense of self-worth and well-being. Even though the epidemic is over 20 years old, considerable misinformation and stigma still persist, and this can manifest itself in hostility toward children with HIV attending school. Further, children with HIV/AIDS tend to be absent from school more frequently than their counterparts, due to both illness and medical appointments. Meeting their educational needs in spite of frequent absence presents additional challenges. Coordinating with

schools to meet the needs of children and youth living with HIV/AIDS is essential for both health and educational development.

In addition, anti-AIDS medications can affect children differently from adults, and HIV-positive children may grow more slowly than other children. Children who know that they have a life-threatening disease may need specialized mental health services. Managing disclosure with children is especially complicated, as parents and caregivers must both explain the illness to the child and help the child explain the illness to others as they navigate disclosure in school and social settings.

While youth with HIV/AIDS must deal with some of the universal problems of living with the disease, such as drug side effects, they also face their own unique problems. Two different groups of HIV-positive youth – those who grew up with HIV from perinatal or early childhood infection and those behaviorally infected as adolescents or young adults – may also be challenged by the disease in different ways. Youth who were perinatally infected may have grown more slowly and matured sexually later than uninfected children.<sup>11</sup> Their educational progress may have been slowed by frequent absences, and HIV's neurological affects also may have created special educational needs. In addition, they may have had to cope with parental death and/or the foster care system.

Young people who were behaviorally infected with HIV most frequently come from two populations already facing stigma and often poverty: young men who have sex with men and young women of color. The subgroups of young men who have sex with men and young women of color who are most at-risk for HIV infection are among the most vulnerable youth in today's society: homeless or runaway youth, juvenile offenders, school drop-outs, and drug users.<sup>12</sup> These young people may already be struggling with securing reliable sources of housing, shelter and food. Given these day-to-day life-and-death priorities, treating HIV infection – which may not cause serious illness for years – may not be a high priority for them.

For all the above reasons, providing these diverse populations – women, children, youth, and families affected by HIV/AIDS – with medical and support services presents considerable challenges and requires a wide range of offerings, including:

- Culturally competent and friendly outreach, which is especially important in identifying HIV-positive youth and bringing them into care;
- Specialized medical and support services teams with expertise in the clinical and social manifestations of HIV disease among these populations;
- Transportation services and easily accessible service sites;
- Language and interpreter services, especially when parents and/or children have limited English proficiency;

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<sup>11</sup> Arthur J. Ammann, "Pediatric Human Immunodeficiency Virus Infection." Immunologic Disorders in Infants and Children. Edited by E.R. Stiehm, H.D. Ochs, and J.A. Winkelstein. Fifth edition, 2004.

<sup>12</sup> Centers for Disease Control and Prevention fact sheet, "Young People at Risk: HIV/AIDS Among America's Youth." Updated March 11, 2002. Available at <http://www.cdc.gov/hiv/pubs/facts/youth.htm>.

- Childcare; and
- Mental health, substance abuse, and case management.

Supportive services such as social work, case management and housing support are integral to successful care and treatment not only for women, children, youth, and families, but also for all people living with HIV/AIDS.

Title IV projects have built effective systems to reach women, children, youth, and families and promote healthy outcomes and support treatment adherence. The reauthorization of the CARE Act must recognize the achievements of Title IV grantees in serving these hard-to-reach communities, including the difficulties of finding them, getting them into care, and keeping them in care. Though much work is being done, the lack of adequate resources for Title IV – and the rest of the CARE Act – impedes a full response to the care and treatment needs of people living with HIV/AIDS. Following is further discussion of Title IV services, the family-centered approach to care, and policy recommendations.

### *Preventing Mother-to-Child Transmission of HIV (MTCT): The Role of Voluntary Testing and Comprehensive Services*

Title IV grantees provide many innovative programs to address the HIV prevention needs of women, children, youth, and families. These include case-finding to bring infected individuals into care, as well as prevention education and services to help promote safer behavior among people living with HIV/AIDS. One of the greatest successes of HIV prevention within Title IV has been reducing mother-to-child transmission of HIV (MTCT).

In the absence of antiretroviral treatment, an infant born to an HIV-positive mother has about a 25 percent chance of becoming infected. In the 1980s and early 1990s in the United States, this meant that, out of the 6,000 – 7,000 HIV-positive pregnant women delivering, approximately 2,000 babies were born annually with HIV. However, in 1994, the groundbreaking results of the AIDS Clinical Trial Group (ACTG) 076 study demonstrated that treatment with AZT could significantly reduce the chance of transmission to 8 percent.<sup>13</sup> As antiretroviral therapy advanced, even further reductions became possible.

Recent reports suggest that MTCT in the United States has been reduced by ten-fold, with approximately 200 infants born with HIV annually.<sup>14</sup> This is an unqualified public health success story – no other category of HIV transmission has achieved such a remarkable decrease.

Title IV projects have had a unique and major role in achieving these reductions, through case-finding for HIV-positive pregnant women, offering them testing, and providing the care and

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<sup>13</sup> Centers for Disease Control and Prevention, “HIV/AIDS Special Surveillance Report: Enhanced Perinatal Surveillance United States, 1999-2001.” No. 4, 2004.

<sup>14</sup> Marc Santora, “U.S. Is Close to Eliminating AIDS in Infants, Officials Say,” *The New York Times*. January 30, 2005.

treatment that enables the reduction of mother-to-child transmission. Title IV projects have crafted an effective partnership of researchers, care providers, and consumers to develop models of care that greatly reduce MTCT. Providing HIV testing with informed consent and providing care through comprehensive care systems for HIV-positive pregnant women have already been tremendously effective. Expanding these services in the reauthorization process provides the best chance for further reduction in MTCT, toward the goal of elimination of MTCT in the United States.

## The Ryan White CARE Act Today

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### *Four Titles and Other Programs: The Structure of the CARE Act*

The Ryan White CARE Act is structured as four major titles and other, smaller programs. Each title is set up as a different funding stream, with different recipients:

- Title I: Provides grants to cities and surrounding areas (eligible metropolitan areas – EMAs) with high AIDS prevalence
- Title II: Provides grants to all 50 states and the territories
- Title II – AIDS Drug Assistance Program (ADAP): Goes to all 50 states and the territories as a set-aside within Title II to purchase medications for people living with HIV/AIDS
- Title III: Provides funding for primary medical care, frequently through community health centers
- Title IV: Provides grants for comprehensive care for women, children, youth, and families
- Part F – Dental reimbursement: Provides for dental services for people living with HIV/AIDS
- Part F – AIDS Education and Training Centers (AETCs): Provides funds for training health care providers
- Special Projects of National Significance – SPNS: Supports demonstration projects on new models of HIV/AIDS care delivery

Titles I, II (base), III, IV, and Part F Dental are considered “care-providing,” meaning their funding is used primarily to provide medical and support services. The Title II set-aside for ADAP is used to purchase medications, and the remainder of the CARE Act is dedicated to training, promotion of best practices, and innovative program models. The CARE Act is administered by the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA).

In fiscal year 2005, the appropriation for the Ryan White CARE Act was approximately \$2.048 billion, an overall increase of about \$28 million (1.3 percent) over fiscal year 2004. However, the funding increase was entirely within the AIDS Drug Assistance Program, and this masks the fact that the care-providing titles all took funding cuts due to an overall rescission of federal funding in the omnibus appropriations bill. In both fiscal years 2004 and 2005, the other programs lost money, with losses in the CARE Act totaling approximately \$28 million. Further, though ADAP has received modest funding increases, these increases are not adequate to meet the existing and growing need for anti-AIDS medications. Overall, the CARE Act every year is being asked to do more and more with less and less.

### *Women, Infants, Children and Youth (WICY) Set-Asides*

To respond to the needs of women, infants, children, and youth (WICY) affected by HIV/AIDS, Titles I and II are structured to include a WICY “set-aside” to provide care specifically for these populations. The WICY requirements ensure that a percentage of CARE Act resources is allocated equal to the percentage that each of the populations – women, infants, children, and youth – constitute within the overall HIV/AIDS epidemic in a given area. Thus, if an area has an HIV/AIDS epidemic in which 35 percent of the cases occur among women, then at least 35 percent of the resources must be devoted to women’s care, and so forth for each of the groups. These funding requirements are coordinated through Title I planning councils, Title II planning bodies, and public health officials.

States and EMAs may request WICY “waivers,” which allow them to count their Medicaid and SCHIP expenditures as meeting the requirements of the WICY set-aside. However, few states and EMAs have exercised this option, and preliminary data suggest that grantees under Titles I and II have been able to meet their WICY requirements, resulting in essential resources being targeted to the WICY populations.

## Title IV: The Unique Structure and Benefits of Family-Centered Care

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### *About Title IV Grantees*

In fiscal year 1988 – “greatly concerned with the increase in the number of pediatric AIDS cases”<sup>15</sup> – the Senate set aside \$5 million for demonstration projects to treat pediatric AIDS. These grants were known as the Pediatric AIDS Demonstration Projects.

The goal of these projects was to develop care and treatment models for children with AIDS, as well as HIV-positive pregnant women and their families. Another impulse in their development was the lack of participation in clinical trials by women and children.

Every year, as the Senate predicted, the number of children with HIV/AIDS grew, and the need for specialized services increased. In 1994, Congress funded these projects under Title IV of the CARE Act, and, in the 1996 CARE Act reauthorization, they were formally incorporated as Title IV. Additionally, Title IV projects were instructed to help enroll women and children in clinical trials and have been successful in that endeavor.

At present, Title IV funds 91 grantees in 35 states, the District of Columbia, Puerto Rico, and the Virgin Islands with \$72.5 million. These grantees provide comprehensive, family-centered care to women, children, youth, and families. Seventeen of these grantees are specially focused on case-finding and enrolling in care HIV-positive adolescents and young adults (ages 15-24). Grants are awarded to many different kinds of institutions, including universities and hospitals, community health centers, and community-based and faith-based organizations. Title IV grant awards range in value from \$250,000 to \$2.3 million.

Title IV is the only title in the CARE Act that is allowed to provide services to uninfected family members of HIV-positive people – AIDS affects the entire family, not just the infected family members. This is especially true when a parent has HIV. That's why Title IV grantees consider the entire family to be the client. In 2001, of the more than 21,000 affected family members needing medical and support services from Title IV, over 14,000 were infants and children of HIV-positive parents.<sup>16</sup>

Title IV grantees usually use a network of providers to meet the needs of women, children, youth, and families. This means that the grantee of record may subcontract services such as medical care, case management, childcare, and transportation, while retaining responsibility for financial oversight, management, and quality of care.

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<sup>15</sup> United States Senate Appropriations Committee, S. Rpt. 100-189, 1987.

<sup>16</sup> Health Resources and Services Administration. “2001 Ryan White CARE Act Title IV Data Slides.” Available at <http://hab.hrsa.gov/reports/TitleIV2001/>.

### *Family-Centered Approaches to Care*

Family-centered care – an approach to providing comprehensive, coordinated, and culturally competent care and services – has been the successful foundation of the Title IV program from its earliest conception as the Pediatric AIDS Demonstration Projects in 1988. Family-centered care is built on partnerships and collaboration between consumers and providers of care and encourages and supports consumer participation in all levels of the care system.

## Reauthorizing the Ryan White CARE Act in 2005: Policy Principles from AIDS Alliance

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### *Defining Our Policy Priorities*

AIDS Alliance engaged in more than a yearlong community process to develop our policy principles for CARE Act reauthorization. In order for AIDS Alliance to speak on behalf of the Title IV community of consumers and providers, we first engaged in several forums to hear directly from the Title IV community.

In early 2004, the executive director engaged in a series of “Town Hall Meetings” across the country to hear from Title IV consumers and providers what’s working well with Title IV (and the CARE Act as a whole) and what needs improvement. The executive director visited nine cities and heard from hundreds of meeting participants. In addition, AIDS Alliance held two forums at our annual conference, Voices. One forum was for Title IV project directors to communicate their concerns, and another forum was for consumers. Finally, board members convened regional conference calls of project directors to discuss programmatic specifics about the structure of the CARE Act.

The concerns from each of those meetings, forums, and calls as identified by consumers and providers were compiled, and the government affairs committee of the board synthesized those concerns into 10 policy priorities for CARE Act reauthorization. The full board then adopted the principles as the basis for AIDS Alliance reauthorization efforts. The 10 principles do not speak to the entirety of the CARE Act but, rather, focus on Title IV and issues most relevant to women, children, youth, and families affected by HIV/AIDS. For some of these principles, we have developed specific legislative language we encourage.

## *Ten Policy Principles and Justifications*

### Title IV Issues:

1. Title IV should be maintained as an independent program, and “family-centered care” must be reemphasized.
2. All populations of HIV-positive youth should be prioritized and provided outreach, care, and prevention services, with emphasis on retaining youth in care.
3. Access to HIV research opportunities for women, infants, children, and youth through Title IV should be maintained, with increased Title IV grantee participation in research priority-setting.
4. Title IV’s unique role in HIV prevention should be affirmed.
5. Negative ramifications from an administrative cost limitation on Title IV projects must be avoided.
6. Access to medical care and case management support services for HIV-positive pregnant women to retain them in care and help prevent MTCT should be enhanced, especially for hard-to-reach populations of women.

### CARE Act Issues

7. The CARE Act’s basic four-title structure should be preserved.
8. Prioritization of care services for women, infants, children, and youth in Titles I and II should be maintained.
9. Collaboration and communication should be expanded across all titles of the CARE Act and between other federal agencies including HRSA, CDC, SSA, CMS, ACF, SAMHSA, NIH, VA, and HUD.
10. As part of a comprehensive approach to preventing mother-to-child HIV transmission (MTCT), voluntary HIV testing protocols for pregnant women, including during labor, should be promoted, and enhanced surveillance of MTCT should be maintained.

## Title IV Issues:

### **1. Title IV should be maintained as an independent program, and “family-centered care” must be re-emphasized.**

The mission of Title IV projects is unique and specific. Title IV cannot be collapsed or combined into any other part of the CARE Act without damaging systems of care that prioritize families.

The existing programs have been very successful in reaching women, children, youth, and families. This program must be maintained independently. In addition, though family-centered care models are widely in use in Title IV, they are not explicitly recognized within the legislation. Recognizing the special nature of considering the whole family to be the client, rather than infected individuals only, is critical to maintaining the quality of services.

Further, Title IV must be prioritized in the appropriations process and given adequate funds for existing projects to grow to meet demand and for new projects to be established.

*Specific legislative proposal:* Section 2671 of the Public Health Service Act (42 U.S.C. 300ff-71) is amended –

- (1) in subsection (d)(1), by striking “for” and inserting “coordinated, family-centered care, including”; and
- (2) in subsection (k), by striking “1996 through 2000” and inserting “2006 through 2010.”<sup>17</sup>

### **2. All populations of HIV-positive youth should be prioritized and provided outreach, care, and prevention services, with emphasis on retaining youth in care.**

All Title IV grantees focus on bringing youth with HIV into care and retaining them in care. As discussed in the “special needs” section of this paper, there are myriad challenges facing HIV-positive young people. Case-finding and bringing them into care is highly challenging, but many Title IV projects have developed innovative techniques to accomplish this goal, including the deployment of peer advocates and outreach workers.

While all Title IV grantees work with HIV-positive youth, in 2000, HRSA launched an initiative to create adolescent-specific Title IV grants. There are now 17 projects specifically funded to focus entirely on HIV-positive adolescents. These programs have

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<sup>17</sup> Title IV was reauthorized in the Ryan White CARE Act Amendments of 2000, however, a legislative drafting error incorrectly amended the years of authorization.

built new, innovative, youth-focused systems of care. The CARE Act should reflect the work being done both generally by Title IV projects and the work being done by these adolescent-focused projects. New resources must be added through the appropriations process to expand efforts targeted to adolescents throughout Title IV and through the adolescent initiative programs.

*Specific legislative proposal:* Section 2671(a) of the Public Health Service Act (42 U.S.C. 300ff-71(a)) is amended by adding at the end thereof the following:

“(3) In the case of youth with HIV, providing health care and other supportive services designed to recruit and retain youth in care. For purposes of this paragraph, the term ‘youth with HIV’ means individuals ages 13 through 24 infected through all modes of transmission including mother-to-child.”

**3. Access to HIV research opportunities for women, infants, children, and youth through Title IV should be maintained, with increased Title IV grantee participation in research priority-setting.**

In the 2000 reauthorization, Congress amended Title IV to broaden the role of grantees in clinical trials and other kinds of research. Since the amendment, Title IV programs have continued to educate clients and link them to research.

As care providers for women, children, youth, and families affected by HIV/AIDS, Title IV grantees have unique insight on the day-to-day needs of these individuals and should be a resource for NIH on research priorities for these groups. Congress should help link Title IV grantees to the research agenda-setting for NIH research on women, children, youth, and families affected by HIV/AIDS. In addition, ongoing technical assistance activities for grantees funded through Title IV should be expanded to assist programs and clients in accessing research planning bodies.

**4. Title IV’s unique role in HIV prevention should be affirmed.**

Title IV provides prevention services as an essential component of family-centered care, including: (1) HIV prevention as part of case-finding to identify HIV-positive people; (2) prevention of mother-to-child HIV transmission; and (3) providing primary and secondary prevention services to infected and affected family members.

In particular two critical populations served by Title IV – HIV-positive youth and HIV-positive pregnant women – are routinely engaged in care through avenues requiring HIV prevention education and case-finding. Identifying HIV-positive youth most frequently happens through street outreach to high-risk young people where HIV prevention and HIV testing services are offered. With HIV-positive pregnant women, the standard of care instructs providers on antiretroviral treatment necessary to prevent MTCT.

These HIV prevention activities remain appropriately within Title IV, given its unique constituencies.

**5. Negative ramifications from an administrative cost limitation on Title IV projects must be avoided.**

Providing comprehensive, coordinated, and culturally competent family-centered care requires greater expenditures on administrative and coordinating functions. At present, Title IV is the only title of the CARE Act not subject to a cap on administrative expenses. This leeway provides for the greater flexibility required in administrating networks of services to ensure that the needs of families affected by HIV/AIDS are met appropriately.

In the 2000 reauthorization, Congress authorized the Secretary of Health and Human Services to study the impact of capping Title IV's administrative expenditures, specifically to examine the definition of "administrative expenditure" and to measure the impact of capping such expenditures on services provided to consumers. HRSA commissioned such a study and, based on that data, proposed capping Title IV's administrative expenditures.

However, significant disagreement existed over whether the data from the HRSA study actually led to the conclusion that limiting Title IV's administrative expenditures would increase the amount of funds available to provide services. Data inconsistencies in the study regarding what constitutes an "administrative expenditure," specifically problems around the inclusion or exclusion of indirect costs in such calculations, led Congress to conclude in the fiscal year 2004 omnibus appropriations bill that the data was not adequate to impose a cap at that time.<sup>18</sup> Congress directed HRSA to re-evaluate the data, and ensure that definitions are precise and that any proposed limitation would not harm Title IV grantees' ability to provide comprehensive, family-centered care.

Recent appropriations cycles have left Title IV with fewer resources than in previous years. However, we agree with Congress that the data presented thus far by HRSA does not clearly show that reducing administrative costs would increase the amount of services available.

HRSA must comply with the 2000 Amendments to the CARE Act and produce quality data for this study. Barring such a development, Congress must insist, as the appropriations report stated, that HRSA be prevented from implementing such a cap until it can be shown that it would not harm grantees' ability to provide quality, comprehensive, family-centered care.

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<sup>18</sup> Conference Committee on Consolidated Appropriations Bill, FY 2004. H. Rpt. 108-401. Jan. 2004.

**6. Access to medical care and case management support services for HIV-positive pregnant women to retain them in care and help prevent MTCT should be enhanced, especially for hard-to-reach populations of women.**

As described above, reductions in MTCT are one of the few great success stories of HIV prevention. No other category of HIV transmission has achieved an eight-to-ten-fold reduction in the United States (from over 2,000 per year in the mid-1990s to approximately 200 at present). Many of these accomplishments were achieved through care provided by Title IV grantees.

However, more work remains to be done. The remaining perinatal infections in the United States likely represent the most vulnerable HIV-positive pregnant women, and therefore the most difficult to reach. CDC data show that more than 50 percent of babies born with HIV in the United States had mothers who knew their HIV serostatus.<sup>19</sup> Thus, identifying HIV-positive pregnant women is clearly not the only barrier to preventing MTCT. Providing HIV-positive women with access to prenatal care that includes intensive case management services designed to support adherence to medical care and treatment is a necessary additional strategy to further reduce incidence of MTCT.

We propose a \$12 million demonstration project in Title IV administered by HRSA to provide grants to institutions to increase the availability of prenatal care for such women, including intensive case management, to help retain them in care and provide the optimal conditions for prevention of MTCT.

*Specific legislative proposal:* Section 2671 of the Public Health Service Act (42 U.S.C. 300ff-33), is amended by adding the following:

“(1) Demonstration Grants. –

“(2) In General. – The Secretary shall award demonstration grants to public and private entities to enable such entities to conduct assessments of the effectiveness of the following strategy in reducing the mother-to-child transmission of HIV:

“(A) Increasing access to prenatal care for HIV-positive pregnant women and providing intensive case management and support services for HIV-positive pregnant women.

“(3) Authorization of Appropriations. – There is authorized to be appropriated to carry out this subsection, \$12,000,000 for fiscal year 2006, and such sums as may be necessary for each of fiscal years 2007 through 2010.”

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<sup>19</sup> Department of Health and Human Services, Office of Inspector General, “Reducing Obstetrician Barriers to Offering HIV Testing.” Pgs. 12-13, April 2002.

CARE Act Issues:

**7. The CARE Act’s basic four-title structure should be preserved.**

We support the CARE Act remaining in its basic four-title structure. The existing system of care serves more than half-a-million people annually and has resulted in considerable reductions in both morbidity and mortality.

The CARE Act’s four titles provide a structure that responds to the HIV epidemic across the country but also focuses on areas with the highest needs. Title II serves as a base, ensuring that some CARE Act funds are distributed in every state and territory according to a formula. The rest of the CARE Act responds based on HIV’s impact within certain geographic areas and demographic communities. Title I provides added resources for the most highly impacted cities, also through a formula. Title III provides resources for primary medical care for HIV-positive people through a competitive grant process in underserved areas, while Title IV provides care for women, children, youth and families, also through a competitive grant process. While inadequate funding has meant that unmet needs persist, the policy rationale informing the four-title structure is sound.

**8. Prioritization of care services for women, infants, children, and youth in Titles I and II should be maintained.**

As discussed previously, both Titles I and II are required to ensure that a percentage of funds equivalent to the proportion of people within the jurisdiction living with HIV/AIDS who are women, infants, children, and youth be “set aside” for services to reach these groups.

Early data suggest WICY is having a positive effect, and we support the continuation of this set-aside as a “floor” for funding services to reach these groups. We recommend that the calculation of the WICY set-aside utilize HIV case data as soon as any portion of the CARE Act begins to use HIV data (as opposed to AIDS case data).

The transition to counting HIV cases is particularly important to women and youth. As the HIV epidemic increasingly affects women and young people, they may be infected more recently than other populations and therefore be less likely to have an AIDS diagnosis. Without AIDS diagnoses, communities with high HIV prevalence could be excluded from WICY counts. Switching to HIV data as soon as possible could correct this imbalance.

We support adding a reporting requirement to evaluate the ongoing efficacy of this provision.

*Specific legislative proposal:*

- (1) Emergency Relief. – Section 2604(b)(4) of the Public Health Service Act (42 U.S.C. 300ff-14(b)(4)) is amended by adding at the end the following:

“(C) Data. – In determining the amount of funds to use for services under subparagraph (A), the chief elected official of the eligible area involved shall use HIV case data (rather than AIDS case data) as soon as the use of such data is adopted for purposes of allocating any other funds authorized under this title.”
- (2) General Grants. – Section 2611(b) of the Public Health Service Act (42 U.S.C. 300ff-21(b)) is amended by adding at the end the following:

“(3) Data. – In determining the amount of funds to use for services under paragraph (1), the State involved shall use HIV case data (rather than AIDS case data) as soon as the use of such data is adopted for purposes of allocating any other funding authorized under this title.

“(4) Report. – Not later than October 1, 2007, the Secretary shall submit to the appropriate committees of Congress a report on –

“(A) the status of HIV case data implementation in relation to the allocation of funds under this subsection and under section 2604(b)(4); and

“(B) if such data is being used for allocating resources under this title, the impact of the transition from AIDS case data to HIV case data on the resources directed to women, infants, children and youth under this subsection and under section 2604(b)(4).”

**9. Collaboration and communication should be expanded across all titles of the CARE Act and between other federal agencies including HRSA, CDC, SSA, CMS, ACF, SAMHSA, NIH, VA and HUD.**

Providing quality care to people living with HIV/AIDS is an endeavor that crosses jurisdictions of multiple funding streams within the CARE Act and crosses the organizational missions of agencies throughout the federal government. At present, coordination is inadequate.

For example, recently the CDC’s Advancing HIV Prevention (AHP) initiative aimed to identify and enroll thousands of HIV-positive people into care as part of a new focus on prioritizing prevention services for people living with HIV/AIDS. However, no new funds were made available for the expected cost of treating these individuals, estimated by HRSA to be between \$4 million and \$8 million per year.<sup>20</sup> That estimate was predicated on just 3,800 to 7,500 HIV-positive people entering care because of AHP – if the initiative was more successful, the cost would be significantly higher.

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<sup>20</sup> Health Resources and Services Administration. Letter from Betty Duke, Administrator, to CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment. May 7, 2004.

These problems inhibit effective policy being crafted and implemented on behalf of people living with HIV/AIDS. Congress should respond by creating mechanisms to establish better coordination among federal agencies.

**10. As part of a comprehensive approach to preventing mother-to-child HIV transmission (MTCT), voluntary HIV testing protocols for pregnant women, including during labor, should be promoted, and enhanced surveillance of MTCT should be maintained.**

As discussed previously, the reductions in MTCT in the United States represent one of the best examples of successful HIV prevention. When offered HIV testing, an overwhelming majority of pregnant women will consent.

The remaining 200 MTCT infections that occur annually in the United States are likely occurring among some of the most vulnerable and disenfranchised women living with HIV. If half these infants had mothers who knew their HIV status, then prenatal HIV testing policy must be designed to reach out not only to the women who do not know their status, but also to those who know or may suspect they are HIV-positive.

Designing systems of care to identify and reach these women relies upon accessibility, honesty, trust, and credibility with consumers. We believe that more pregnant women accept HIV testing if they are offered information about the importance of HIV testing for their own health and the health of their child. This also must be accompanied by available, accessible care services should the woman test HIV-positive, and these services must be ongoing after the child is born.

Every HIV infection in an infant should be treated as a sentinel public health event requiring study to determine where the safety net failed. Enhanced HIV surveillance programs in areas with high rates of MTCT should be expanded, and the critical role of rapid testing during labor and delivery must also be emphasized. The prenatal testing policy provisions in Title II must ensure that all pregnant women are offered an HIV test, that they know they are being tested, and that health care providers give pregnant women sufficient information about HIV on which to make a meaningful choice to test. The goals of any prenatal testing policy must be to identify and engage HIV-positive women in care for themselves and their children and reduce mother-to-child transmission of HIV.

## *Existing Legislation*

AIDS Alliance is profoundly grateful for having had the opportunity to work with Senators Dodd (D-Conn.) and Bond (R-Mo.) on the *Children and Family HIV/AIDS Research and Care Act of 2004*. The Senators and their staff took a deep interest in HIV/AIDS as it affects children and families in the United States, and this legislation (S 2892 – 108<sup>th</sup> Congress) resulted from their efforts. Together with the Elizabeth Glaser Pediatric AIDS Foundation and the American Academy of Pediatrics, AIDS Alliance was able to provide input to the Senators about some policy priorities for serving children and families affected by HIV/AIDS.

The five titles of the *Children and Family HIV/AIDS Research and Care Act of 2004* reflect many of AIDS Alliance's highest priorities for CARE Act reauthorization:

- Title I of the bill would reauthorize Title IV of the CARE Act and prioritize family-centered care.
- Title II would codify into law the work done by the adolescent-focused Title IV grantees.
- Title III would reauthorize the WICY provisions in Titles I and II of the CARE Act, while requiring data be moved to HIV cases when feasible.
- Title IV would set up demonstration programs for providing comprehensive care to HIV-positive pregnant women as part of MTCT efforts.
- Title V would create a research initiative ensuring that any HIV vaccine candidate products would be tested for their safety and efficacy for pediatric use, as well as prioritize research on the long-term effects of anti-AIDS drugs on children, the health needs of perinatally-infected HIV-positive children, the transition to adulthood for HIV-positive children, and safer treatment options for HIV-positive children.

We hope to see this legislation re-introduced in the 109<sup>th</sup> Congress. Its combination of policy issues recognizes that both care and research are critical to the lives of women, children, youth, and families affected by HIV/AIDS. We strongly support legislative language from this bill being used in reauthorization of the CARE Act.