



## **Ryan White CARE Act Reauthorization: Where We Stand**

*AIDS Alliance for Children, Youth and Families' Reauthorization Priorities and Concerns*

### **Title IV of the CARE Act is Essential for Women, Children, Youth and Families**

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was named after an adolescent that succumbed to HIV infection in 1990. That same year, Congress created the largest federal discretionary HIV/AIDS treatment program in Ryan's honor. The program has a four-title structure, each targeting different populations and service providers. Title IV of the CARE Act serves women, children, youth and families affected by HIV/AIDS. The program's total appropriation of \$72.5 million is distributed among 91 grantees across the country. Each year, 53,000 women, children, and youth benefit from Title IV services, which often include medical care, case management, childcare, and transportation. Eighty-eight percent of consumers are of people of color and 30 percent are under the age of 13.

### **Reauthorization Recommendations**

The CARE Act, as a discretionary program, requires reauthorization every five years. The current legislation will expire September 30, 2005. AIDS Alliance articulated four major positions for CARE Act reauthorization in its March 2005 position paper "Renewing the Commitment:"

1. Maintain the four-title structure
2. Prioritize care for women, infants, children, and youth (WICY) in Titles I and II
3. Enhance communication among all Titles and relevant federal agencies
4. Improve prevention and surveillance of mother-to-child HIV transmission (MTCT)

AIDS Alliance also proposes six specific issues for reauthorization of Title IV:

1. Maintain Title IV as an independent program, emphasizing family-centered care
2. Prioritize all HIV-positive youth in care and prevention
3. Increase access to HIV research for women, infants, children and youth through Title IV
4. Affirm the unique role of Title IV in HIV prevention
5. Protect administrative cost structure to assure efficient operation of services
6. Enhance care for HIV-positive pregnant women, for retention and prevention of MTCT

The full text of "Renewing the Commitment" can be found at [www.aids-alliance.org](http://www.aids-alliance.org).

### **Reactions to Administration's Principles**

In July of 2005, the Administration announced its principles for reauthorization of the CARE Act. Some of the proposed principles have direct implications for Title IV's capacity. For example, the principles stress an *increase in flexibility* of CARE Act dollars. This is entirely consistent with Title IV's intent. Title IV is flexible enough to arrange for transportation, child care, and case management. Thankfully, the Administration's principles reflect the need for such specificity. The principles also advocate prioritizing *the needs of people of color*. With people of color representing 88 percent of clients served, Title IV has a long history responding effectively to the needs of HIV-affected families, women and youth of color.

Among the proposed principles is a prioritization of *core medical services*. This is a difficult assertion for Title IV, which requires a broad range of services to deliver effective care. In addition, the needs of HIV-positive individuals and families differ from community to community – because of varied costs of living

and the availability of other services and other payers. Therefore, CARE Act programs, consumers, and planning councils should define core medical services independently for their respective communities.

CARE Act funds are intended to be the *payer of last resort*. For virtually all Title IV consumers, medical attention is covered through other insurance mechanisms, such as Medicaid or other Titles of the CARE Act. (Eighty percent of Title IV consumers receive medical care paid by Medicaid.) Title IV dollars are used to make medical care more accessible, through child care, transportation, or other support services. Without the logistical support and care coordination provided by Title IV, medical attention is beyond the reach of many women, children, families and youth served. Other programs do not provide this flexibility, which leaves Title IV as the last, and only, payer of these services.

In a recent survey of Title IV projects, AIDS Alliance found that for projects to meet a 75 percent threshold of funding prioritization for core medical services, the definition of such services must include: primary/specialty medical care, psychosocial support, logistical support/care coordination, and outreach/case management. (89 percent of projects would meet the 75 percent threshold under this broad definition.) A definition of core medical services, if required to be defined in the CARE Act legislation, should reflect the current broad list of services crucial to the health of Title IV consumers.

### **Title IV Plays Unique Prevention Role**

Title IV plays a critical role in HIV prevention in the United States and in the potential elimination of pediatric AIDS. Prevention of mother-to-child transmission (MTCT) has always been a priority of Title IV programs. Since the early 1980s, Title IV-affiliated programs have led the nation in reducing the number of babies born positive to HIV-positive mothers from 2,000 to 200 annually. This success rate, resulting from longstanding success in the pediatric AIDS field and, later, incorporation of antiretroviral therapy during pregnancy, is renowned as the prevention tool linked with the most definitive outcomes.

During the same 2005 survey previously referenced, it was found that, on average, 38 percent of Title IV projects' clients are HIV-negative. Often times, these individuals have family members who are HIV-positive, or are living in areas with disproportionate infection rates. Title IV programs build trust with communities that strategically place them closer to those at greatest risk of transmission.

### **Example of a Title IV Project**

An exemplary Title IV project is the Dallas Family Access Network, located in Dallas, TX. The Network is a coalition of 13 medical care and social service agencies that promotes a system of care for HIV-positive clients and those affected by HIV. Some organizations included in the network are: the UT Southwestern Medical Center (which serves as the lead organization – coordinating the grant making for the other 12 affiliates), the AIDS Interfaith Network, the Child and Family Guidance Centers, and the Visiting Nurses Association. Collectively, these organizations strive to address all the unique needs of women, children, families and youth affected by HIV in the Dallas, TX area.

In addition, the UT Southwestern Medical Center established an innovative Title IV program in 2001 called Youth Angle. The program targets perinatally infected youth aging out of the pediatric care setting and newly identified HIV behaviorally infected youth, all aged 13 – 24. Youth Angle's collaborative model actively engages in case finding and provides primary medical care, OB/GYN care, social services, substance abuse counseling, support groups, life-skills training, and formal linkages for outreach with the public school system and faith-based organizations. Title IV's current structure, most importantly its flexibility and comprehensive nature, has fostered the intent of such programs to successfully and wholly address a specific community's HIV prevention and treatment needs.