

The Grady Family Clinic in Atlanta, GA, provides comprehensive HIV/AIDS care to more than 2,000 women and children. The clinic also participates in the wider “Family Circle Network” of citywide Part D providers.



Program Origins

PART D Services for Women, Infants, Youth, Children, and Families

Title IV (now Part D) played a leading role in reducing mother-to-child transmission of HIV— from as many as 2,000 babies born HIV positive in 1990 to roughly 200 cases in 2005.

● Part D: Women and Families in a Circle of Care

Circle of Care in Philadelphia inaugurated an annual Arbor Day celebration in 1990, planting a tree each year in honor of a child with HIV/AIDS who had received services from the agency and died during the previous year. “It’s a beautiful grove,” said Circle of Care’s Alicia Beatty, who noted that celebrations continued for 10 years until the first year the agency did not lose a child.¹

Part D of the Ryan White HIV/AIDS Program has played a key role in the development and provision of the health care and support services at Circle of Care and dozens of other agencies and institutions that focus on women, infants, children, and youth living with and affected by HIV. Like most other components of the program, Part D has its roots in an initiative that predated passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

Origins of Part D

“Greatly concerned with the increase in the number of pediatric AIDS cases,”² Congress first acted to address pediatric cases in 1987 by providing \$5 million for the Pediatric AIDS Demonstration Projects in the FY 1988 budget. At the end of 1987, 737 pediatric AIDS cases had been reported to the Centers for Disease Control and Prevention, up from 410 cases at the end of 1986.³

It was also a time of stigma and discrimination faced by children and families. Beatty recalls that one of the first HIV-infected babies buried in Philadelphia was buried in a Styrofoam cooler because none of the local funeral directors wanted to take the body. A primary architect of the demonstration program was Senator Arlen Specter (R-PA), who played a role in drafting the guiding legislative language.⁴

Addressing Unique Needs of Women and Families

The goal of the demonstration project, which originally supported 13 programs, was to develop care and treatment models for children with AIDS and HIV-infected pregnant women and their families as well as to enhance the participation of women and children in HIV-related clinical trials.⁵



In the years since AZT first proved its efficacy, mass production of it and other anti-retroviral drugs has helped lower treatment costs. At the same time, simplified treatment regimens and dosing schedules have helped many patients achieve higher levels of drug adherence and generally healthier outcomes.



In March 1990, actor Paul Michael Glaser and his wife Elizabeth testified before the House Budget Committee Task Force on Pediatric AIDS. Elizabeth Glaser, who co-founded the Pediatric AIDS Foundation, contracted AIDS from a 1981 blood transfusion and died in December of that year from the disease.

The program was housed at HRSA's Maternal and Child Health Bureau. From the outset, it was designed to address the unique needs of women living with HIV/AIDS and their children and families. Parents living with HIV must manage their own care while caring for their children. Coordinating child care, transportation, and medical and social service appointments can present major challenges, especially for single parents or if a child or partner is also infected. Children living with HIV/AIDS also face a range of special issues, including delayed growth and development, mental health needs, and the unique side effects of HIV medications on children, among others.⁵

Speaking of her experiences in the program's early days at Children's Hospital in New Orleans, Beth Scalco says, "When I started working in the pediatric AIDS program, we did not have AZT [zidovudine], and we were

seeing 25 percent of women with HIV passing the virus to their children. We were seeing really sick children and children who died very quickly. A lot of our work was also trying to keep a child in a family, trying to help moms who were sick to have the support they needed to care for their kids, trying to place kids in foster care and with other relatives."⁶

Pioneering Work of Elizabeth Glaser

The inclusion of the demonstration project in the Ryan White CARE Act in 1990 was largely the result of the efforts of Elizabeth Glaser, founder of the Pediatric AIDS Foundation.⁷ Glaser was a vocal advocate for investments in research on therapies to prevent mother-to-child transmission of HIV and to treat infected children. At the time, Representative Henry Waxman (D-CA) was leading efforts to pass the CARE Act in the House of Representatives. At the suggestion of Waxman's staff members, Glaser enlisted Representative Norman Lent (R-NY), a key Republican on the Energy and Commerce Committee, to build stronger bipartisan support for the bill. Lent became an advocate for the bill and took the lead on pediatric provisions during the House debate.⁸

Demonstration Grants Become Law

Ultimately, Title IV authorized demonstration grants to conduct clinical research on therapies for children and pregnant women with HIV and provide health care, case management, and support services for these patients and their families. Notably, Title IV was the only component of the act to fund services for non-infected family members. Although the program was integrated into law on passage, it was funded independently of the CARE Act through 1993. Congress transferred the funding for the demonstration program into Title IV in FY 1994.

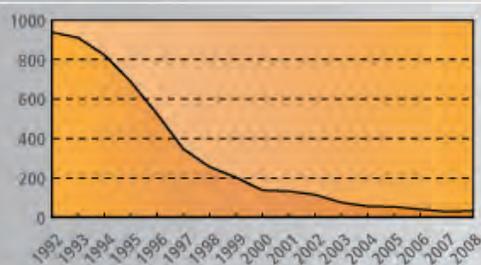
As passed, Title IV included provisions that were never funded, including health systems research, evaluation at the Agency for Healthcare Policy and Research, and studies on HIV partner notification and HIV disease in rural areas.⁹

NUMBERS OF AIDS CASES¹³ CHILDREN <13 YEARS OLD

ESTIMATED NUMBERS of AIDS CASES¹³

Children <13 Years Old
1992–2008

United States and
5 U.S. Dependent Areas



Year	Number of Cases
1992	949
1993	921
1994	832
1995	695
1996	529
1997	349
1998	257
1999	203
2000	137

Year	Number of Cases
2001	132
2002	114
2003	74
2004	55
2005	52
2006	39
2007	27
2008	31

A Pivotal Moment in Perinatal Care

A pivotal moment in the history of Part D occurred when researchers were able to prove the efficacy of AZT in preventing mother-to-child transmission of HIV. Proof came in 1994 from a Federally funded clinical research protocol known as AIDS Clinical Trials Group study 076 (ACTG-076). Part D-funded programs, some of which had been involved in the research, seized upon those findings. As Assistant Secretary for Health Philip R. Lee, said at the time, “In response to these important findings about the use of AZT in the perinatal setting, these programs will also emphasize prevention and early intervention of women and their children, and the integration of HIV prevention and treatment into broader systems of primary care.”¹⁰ Ultimately, the programs played a leading role in reducing mother-to-child transmission of HIV—from as many as 2,000 babies born HIV positive in 1990 to roughly 200 cases in 2005.^{11,12}



With the dramatic decline in perinatal transmission of HIV, Part D programs have gradually shifted their focus to the family unit, regardless of whether or not the child is infected.

Predictably, the decline in perinatal transmission of HIV helped bring about a gradual but equally dramatic decline in the number of reported AIDS cases in all children under age 13 (see chart above). The declines can be attributed both to the efficacy of AZT and to aggressive efforts to reach out to pregnant women and their families through Part D programs.

Reauthorization Expands Populations Served

In the reauthorization of the Ryan White CARE Act in 1996, Title IV changed from a demonstration project to a grant program. Rather than authorizing actual clinical research, as did the original act, the new provisions authorized funded programs to provide “opportunities for women, infants, children, and youth to be voluntary participants in research of potential clinical benefit to individuals with HIV disease.” This language also offered a more expansive definition of populations served, which had been listed in the original version of the bill as pediatric patients, pregnant women with HIV, and their families. The 1996 provisions removed specific reference to community health centers as potential grantees but maintained clear language that service models had to include outpatient health care; case management; inpatient referrals; and wraparound services, such as transportation and child care, to enable participation in the program.

Family-Centered Approaches

“Initially, the [Title IV] program was very focused on children who are HIV infected, but over the years it expanded to a family-centered approach,” says Scalco. “With the decline in perinatal transmission, the focus on the program has to be much more working with women, and especially pregnant women, to make sure they access testing and treatment and continue to work with the family unit, regardless of whether or not the child was infected.”⁶

To that end, Part D programs consider the entire family their client, helping all family members weave together a network of medical care and support services to address



The Title IV (Part D) Youth Initiative supports 17 programs nationwide specifically tailored to the needs of young people living with HIV/AIDS. Programs provides a nurturing environment that offers social interaction and emotional support in addition to HIV/AIDS care.

PART D: HISTORICAL HIGHLIGHTS

- **1988**
AIDS Demonstration Projects include \$5 million for projects addressing pediatric AIDS cases.
- **1990**
The Ryan White CARE Act includes demonstration grants for clinical research on HIV therapies and coordination of care and services for HIV-positive women, children, and families.
- **1996**
The Ryan White CARE Act is reauthorized, and Title IV becomes a mainstay in the legislation.
- **1999**
HRSA's HIV/AIDS Bureau funds an initiative in response to the growth in the number of HIV-infected youth.
- **Today**
Part D serves more than 53,000 HIV-affected women, children, youth, and families.

their health and social needs. At the heart of the program from the beginning, the commitment to a family-centered approach to care has deepened as the epidemic has matured. Key to the success of this care model is active consumer involvement and collaboration between consumers and providers. To meet the needs of their families, Part D programs usually contract with a network of providers, often subcontracting services ranging from medical care and case management to child care and transportation.⁵

New Emphasis on HIV-Positive Youth

In 1999, in response to the alarming growth in the number of HIV-infected youth being identified, a Youth Initiative was added to Title IV. It supports 17 youth-specific programs. Currently, 73 Part D programs in 34 States, the District of Columbia, Puerto Rico, and the Virgin Islands, serve more than 80,000 clients, 86 percent of whom are racial minorities.¹⁴ The 2006 reauthorization placed a 10-percent cap on administrative costs but did not require Part D grantees to spend at least 75 percent of their funds on core medical services, as required of the other major service delivery components of the Ryan White Program.

[See Part D funding information by State.](#)

[Read more about Part D.](#)

Credits and Sources

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Photography

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