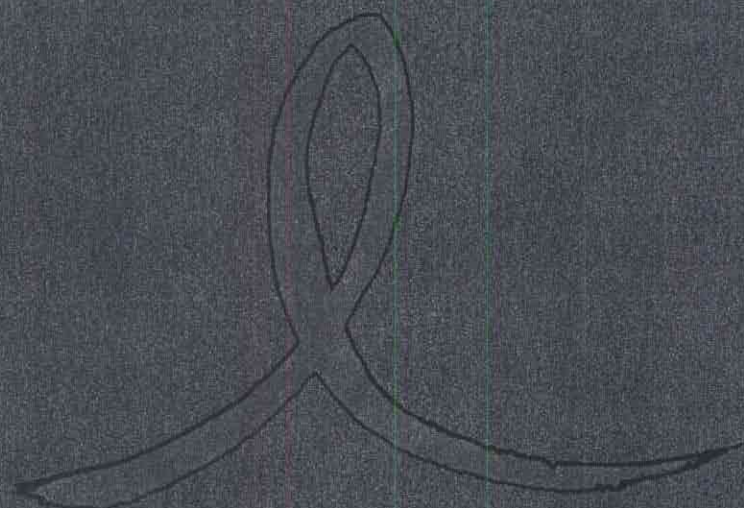


PLANNING
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Report of a National Conference
sponsored by Casey Family Services
and The Annie E. Casey Foundation

Executive Summary

MEETING THE NEEDS OF CHILDREN,
ADOLESCENTS, AND FAMILIES AFFECTED
BY HIV/AIDS

For more than 20 years, Casey Family Services has assisted vulnerable children and families. Today the agency operates divisions in Connecticut, Maine, Maryland, Massachusetts, New Hampshire, Rhode Island and Vermont and offers an array of services and programs including

- long-term and treatment foster care
- transition from foster care to independent living
- post-adoption services
- family advocacy and support
- family preservation and reunification
- assistance for teen parents and for families affected by HIV/AIDS

Casey Family Services seeks to improve the lives of at-risk children and to strengthen families and communities by providing high-quality, cost-effective services that advance both positive practice and sound public policy.

The drawings and others presented throughout this summary were contributed by children in "Family Connections," a program for AIDS-affected families operated by Casey Family Services in Bridgeport, CT

The AIDS epidemic has grown rapidly since the disease was first identified in 1981. Through the end of 1997, more than 640,000 AIDS cases in the United States had been reported to the Centers for Disease Control and Prevention. For every reported AIDS case, there are approximately two or three more cases of people living with HIV. Because AIDS predominantly affects young adults in their prime childbearing years, the disease has had a tremendous although insufficiently recognized, impact on children and families. Most of the children who survive the death of a parent from AIDS, or who live with HIV-infected family members, are not themselves HIV-infected.

Professionals working in social services, education, health, law, public policy, and other disciplines came to a conference convened by Casey Family Services, the operating arm of The Annie E. Casey Foundation, on December 11-12, 1997, to explore key issues, strategies, and policy implications for families affected by HIV/AIDS. The goals of the conference were 1) to raise awareness among administrators, policy makers, and the general public of the needs of children and families affected - not only infected - by HIV/AIDS, 2) to provide a forum for sharing community, state and national perspectives on plausible responses to these needs, and 3) to identify successful and replicable efforts to improve services and impact policies geared to the needs of families with HIV/AIDS.

The diverse group of approximately 250 conference participants, representing a variety of perspectives and agendas, engaged in educational, emotional, and sometimes controversial discussions during two plenary panel discussions and 30 workshops. During the first panel discussion, AIDS researchers and policy analysts presented current data on children and families affected by HIV/AIDS, discussed the impact of welfare reform legislation on these families, and explored the implications of using managed care organizations to deliver services to affected families. The second panel discussion focused on strategies for advocacy and presented model state legislation from the perspectives of advocates and state legislators. In keeping with the conference goal of stimulating dialogue, participants also attended workshops during three breakout periods, where they shared personal experiences, described specific research or programs, debated ethical issues, and discussed challenges in working with families with HIV/AIDS.

- *Coordinated health, mental health, and social support services.* Individuals must have access to the most up-to-date medical care. Equally important, they need comprehensive services that include family counseling, permanency planning, and child care provisions. These needs require coordination from doctors, mental health professionals, and social workers.

Policy Recommendations

Speakers welcomed the initiatives by policy makers, researchers, health professionals, educators and social workers in the fight against HIV/AIDS. However, they emphasized that these efforts mark only a beginning. To extend and increase the impact of these initiatives, the conference steering committee has identified policy recommendations that emerged from the conference discussions in several critical areas:

- *Family Support.* Public and private agencies should insure that a range of family support services is made available to families with HIV/AIDS. Services should address the needs of the infected person, family and extended family members, as well as new caregivers. Funding for services should be increased.
- *Children's Mental Health Needs.* Insurance programs should not set arbitrary limitations on the type and amount of mental health services available to children. A range of mental health services should be available to assist children during the illness of their parent and throughout the stages of loss, grieving, and transition. Since grief reactions are likely to recur as a child develops, mental health services should be available at each developmental stage.
- *Transition Services.* Funding for HIV/AIDS services generally focused on assisting the infected individuals, making them eligible for assistance in such areas as housing, rent subsidies, and in-home health services. When the adult dies, services are eliminated, leaving the children and other family members without supports. This may mean that in addition to the trauma of death, a family may also be facing hardships in such form as the loss of housing, reduction in household income, and elimination of in-home healthcare.



Grandma says my mom went to heaven, but I miss her a lot.

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I hate drugs 'cause that's how my ma got AIDS

Speakers emphasized the importance of current local, state, and national efforts to improve the quality of care for HIV/AIDS-affected families. For example, the city of Baltimore has combined federal and local funds to support community-based organizations that provide care and prevention services. On a national level, several initiatives had had positive or potentially positive results on health care services and the families who use them:

The Centers for Disease Control and Prevention implemented guidelines in 1995 recommending voluntary prenatal HIV counseling, testing and treatment when needed. Since then, the number of children diagnosed with AIDS from perinatal transmission has fallen by almost 50 percent.

President Clinton has committed to implementing a new Food and Drug Administration rule requiring drug companies to test new therapies for children in the hopes that new antiviral drugs can be developed to enhance children's quality of life.

Federal funds allocated under the Ryan White AIDS Care Act can be used to develop comprehensive and family-centered care networks. For example, Baltimore received \$38 million in federal funding for more than six years to increase outpatient care and support services for low-income people with HIV/AIDS.

Crosscutting Themes

Several crosscutting issues and themes emerged throughout the conference:

- Despite reports of recent decreases in deaths from AIDS, cases of HIV infection are continuing to rise among certain populations, especially young women of color. Increasing numbers of children and youth live in families affected by not only HIV/AIDS, but also by the multiple problems that often accompany the disease, including substance, physical and sexual abuse. As more and more children are orphaned to this devastating disease, the need for comprehensive, coordinated services that address the physical and mental health needs, education, and permanency planning for affected children and families becomes more crucial.



My ma is the best mom in the world, and I'm not gonna let her die of AIDS.



I miss my mom since she died.

- Community, state and federal collaborations have begun to address many needs of these families through funding, policy, and service initiatives that offer potentially replicable components. Links between HIV/AIDS services and state child welfare systems, schools and mental health clinics and social and legal services are some of the connections that are developing to secure appropriate interventions for individuals and families in need. Service providers are attempting to create culturally sensitive services that are oriented to both families and individuals and respond to the multiple needs of affected families.
- Important lessons still can be learned from model service and policy initiatives. Continuous education and communication are essential not only to surmount existing barriers, but also to create comprehensive, effective future responses to the needs generated by the AIDS epidemic. Strategies that build a solid understanding of the issues by sharing knowledge, perspectives, and experiences among providers and policy makers can improve the lives of the children, adolescents, women, and men who are coping with this devastating disease.

A Call for Action

Throughout the conference, speakers identified initiatives that would ensure adequate care for children and families infected and affected by HIV/AIDS.

- *Flexible family-centered programs that respond to the social, psychological and legal needs created by advances in HIV/AIDS treatments.* Unlike the early years of the AIDS epidemic when most of the people who developed AIDS died relatively quickly, there is now the potential for both prolonged survival and improved quality of life. These hopeful developments also bring the realities of long-term, rigorous treatment, side effects, and uncertainties. For children and youth living in families with HIV/AIDS, social services should be geared toward helping them live with chronically ill, rather than an immanently dying parent. Nevertheless, permanency planning remains an essential goal.
- *Family-centered services that reflect the needs of diverse communities and are sensitive to cultural differences.* People from differing racial, ethnic, economic and religious backgrounds may have different concerns or needs in dealing with HIV/AIDS.

- *Custody.* Even with the new medications, the future for anyone with HIV/AIDS is very uncertain. Short-range plans need to be in place for children's care in the event of the parent's hospitalization. Permanent plans should be in place to insure a stable future for the children in the event of a parent's death. Relatives are often willing to become permanent caretakers for affected children. For many relatives, particularly those living in poverty, caring for additional children requires financial assistance.

- *The Child Welfare, Juvenile Justice and Mental Health Systems.* State, child welfare, juvenile justice and mental health agencies do not track AIDS-affected children who come into their systems. Without an understanding of how many and who these children are, these agencies cannot insure that AIDS-affected children will receive the services they need to assist them to cope with the trauma of their parents' illness and death.

- *Welfare Reform.* Exemptions from work requirements should be provided under Temporary Assistance to Needy Families (TANF) for individuals suffering from long-term debilitating illness, such as HIV/AIDS, and for family members who provide for their care and the care of their children.

- *Special Medical Needs.* States should address the special medical needs of people with HIV/AIDS in their Medicaid managed care plans and provide linkages and easy access to the substance abuse, mental health and other supportive services that may be needed, including bereavement support.

- *Training.* Federal and state funding should be made available to develop training curricula and materials and to implement training to a broad range of service providers who work with families affected by HIV/AIDS.

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The entire report is
available upon request.



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