



**National Resource Center for
Family-Centered Practice and Permanency Planning**
at the Hunter College School of Social Work

Information Packet:

Parents with HIV/AIDS and Their Children in the Child Welfare System

By Jordan Thaler

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**129 East 79th Street • New York, NY 10021
TEL 212/452-7053 • FAX 212/452-7475
www.nrcfcppp.org**

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"The recognition of a disease and its emergence as a leading cause of death within the same decade is without precedent." (CDC, 1992)

Summary

The number of AIDS-related deaths has greatly decreased with the advent of drug treatments, and current public perception has likewise diminished in its consideration of the disease as a life-threatening, terminal illness. Statistics which continue to examine the ongoing shift in populations affected by the epidemic report that the fastest growing rate of new infection is among women of childbearing age. According to records maintained by the Centers for Disease Control and Prevention (CDC), most of the 64,000 women living with AIDS in the US are mothers (cited in Bauman, Camacho, Silver, Hudis and Draimin, 2002). In 2001, AIDS was the fourth leading cause of death among women between the ages of 35 and 44 and the number one cause of death for African American women aged 25–34 years (Centers for Disease Control and Prevention [CDC], 2005). It is clear from these numbers how enormous the impact of HIV/AIDS has become to issues concerning child welfare. By the year 2000, as many as 125,000 children and adolescents in the United States lost their mothers to AIDS; a third of those reside in New York City (Marsh, 2003).

This information packet seeks to examine the significance of these facts and the implications for

- The relationship between infected parents and their children
- HIV-affected family involvement in the child welfare system
- The need for customized psychosocial services for parents and children, financial assistance, social support services, and access to legal options.

Particularly important is the need for creating and supporting alternative approaches to permanency planning for parents living with HIV/AIDS. Children who have lost parents to AIDS, unlike those whose mothers have died from any other disease, have often been labeled as "AIDS orphans" due to the lack of adequate plans or support systems in place for the care of these children in the event of a parent's death (Marcenko and Samost, 1999).

Literature Review

A significant fact that can be drawn from a partial literature review, consisting of both books and journal articles, on the topic is that almost nothing exists prior to 1993. This most likely points to the enormous demographic shift in affected populations in the last ten years, as well as the systemic societal neglect characteristic in dealing with issues predominantly affecting women and children; particularly those of color. The earliest articles, including *Women and HIV: An Emerging Social Crisis* (Stuntzner-Gibson, 1991) and *The Effects of AIDS on the Family System* (Cates, Graham, Boeglin and Tiekler, 1990) are contextually important because they foretold the effects the disease would have on the family unit, child welfare, sexuality and reproduction – which have been realized in full a decade later – as well as exploring specific implications for social work practice in helping to prevent disease in addition to the need to provide quality services to those already infected.

These articles are chronologically followed in this review by three books, *A Death in the Family: Orphans of the HIV Epidemic* (Levine, 1993), *AIDS and the New Orphans (Coping with Death)* (Dane and Levine, 1994) and *Forgotten Children of the AIDS Epidemic* (Geballe, Gruendel and Andiman, 1995). *A Death in the Family* is a written text that largely grew out of a conference, held by The Orphan Project and United Hospital Fund, which was convened to investigate the crisis from a psychosocial and legal point of view. It introduces the concept of standby guardianship as an option for the welfare of those children of terminally ill parents; cites some service models established as early as 1993; and includes a resource guide index for the New York City area, which has been identified as most affected, having at least one third of the roughly 125,000 children who have lost a parent to HIV/AIDS. *AIDS and the New Orphans (Coping with Death)* is an anthology of chapters written by multiple contributors addressing the psychological impact of parental loss on the stages of childhood development as well as confronting issues of spirituality and culturally specific challenges for Latino and African American communities. It includes a selected resource guide of AIDS organizations, child welfare organizations and professional groups for the purpose of aiding the reader in obtaining additional information and referrals for services. *Forgotten Children of the*

AIDS Epidemic is another anthology, which focuses on the impact of HIV/AIDS on the family unit, particularly children. Citing that "for every child directly *infected*, many more are deeply *affected* by loss of parents, siblings, other crucial caregivers, and all the stabilizing factors that may spell the difference between a healthy childhood and disaster"(Geballe et al., ix), these chapters of diverse authorship put a very human face on discussions of the topic, including first person accounts of infected parents and affected children. This book also contains an extensive bibliography helpfully separated by subject matter, (i.e. legal resources, child and family response and coping) as well as a list of children's books, some that specifically discuss HIV/AIDS.

Two workbooks created by the Child Welfare League of America have been included in this partial literature review for the specificity of the audiences they address – unlike the prior texts, whose anticipated value might be by a readership consisting of social workers, teachers, school nurses, attorneys and judges, particularly those involved in juvenile justice, among others. *Because You Love Them* is personalized to assist (1) HIV-positive parents in reflecting on circumstances in order to adequately plan for their children's future and (2) the many professionals who provide services to these parents. It allows for independent as well as collaborative involvement in all sections, stressing that the use of the guide is a "long-term process and [a] commitment," but parents can use the planning guide by themselves or with professionals in support groups and counseling sessions (Merkel-Holguin, 1994, 1).

Children who Lose Their Parents to HIV/AIDS is a companion piece that provides practice guidelines to agencies handling adoptive and kinship placement, and specifically addresses the issues involved in placing children who lose their parents to HIV/AIDS with kin and with adoptive families. (It is worth noting the existence of an additional CWLA workbook, *Because...Somebody Loves Me* (Hershfield and Ward-Wimmer, 1999), for children 6 to 10 years of age who are facing the loss of a parent to HIV/AIDS. While not available for in-depth review at the time of the writing of this issue brief, the knowledge of its existence has been included in the bibliography because of its certain value in helping HIV-affected children to express and explore the complex emotions of loss, grief, anger, sadness and confusion).

The Social Welfare of Women and Children with HIV and AIDS (Legal Protections, Policy and Programs) (Stein, 1998) is an in-depth reporting and analysis derived from federal statutes that protect the civil rights of women and children with HIV and AIDS and identifies the financial, medical and social services that are available to them. Some selected state statutes illustrate matters such as child custody, testing for HIV and confidentiality of medical records.

Children and HIV/AIDS (Anderson, Ryan, Taylor-Brown and White-Gray, 1998) is a text which was originally released as *HIV/AIDS and Children, Youth and Families: Lessons Learned* (a special issue of the journal *Child Welfare*) as a composite of articles intended as a resource to professionals within the child welfare field serving children and families whose lives are touched by HIV and AIDS. Additional journal articles written in the last four years are included in the bibliography of this information packet, addressing issues which include behavior problems in school-aged children of mothers with HIV/AIDS, the burden of social stigma for affected children and caregivers, the accompanying stressors experienced by grandparents and other relatives caring for children affected by the epidemic, infected mothers' adaptation to the role changes of motherhood, predictors in child custody planning for affected families, proposed initiatives for healthy children orphaned by the disease, and the personal experiences of the challenges of parents living with HIV/AIDS.

National Model Programs

These four models have been chosen for their multifaceted service provisions of medical, financial and social support in addition to legal assistance.

Families Connecting for Kids (Denver, CO)

Families Connecting for Kids is a program created by the Adoption Exchange, also in Denver. The program provides a range of services to HIV-affected families that are designed to support the family as a unit throughout its struggle with the disease. The program provides information and counseling regarding the legal options families have when planning their children's future, case management support, referrals, food vouchers, mass transportation assistance, support groups and social activities. The agency has an extensive network of counselors and lawyers who are willing to provide services to families on a pro bono basis. The staff also helps coordinate medical and social services for the families.

Contact:

Adoption Exchange
925 South Niagra Street, Suite 100
Denver, CO 80224.
(303) 755-4756 / (800) 451-5246
(303) 755-1339 – fax
www.adoptex.org

Living Legacy/Boston Pediatric and Family AIDS Project (Roxbury, MA)

Living Legacy works collaboratively with the Dimock Community Health Center and a Legal Aid agency as well as The AIDS Law Clinic of The Hale and Dorr Legal Services Center of Harvard Law School to provide family-centered, home-based counseling to HIV-infected parents to help them to plan and prepare for the future care of their children. Social workers provide home-based counseling to family members on issues related to HIV-education, permanency planning, disclosure, guardian choice, family conflict, grief, and death and dying. The agency works with the clients to mentally and emotionally prepare them to make plans for their child's future. In addition, the agency encourages the parents to put together scrapbooks and

videotapes of memories for the child. The agency collaborates with the program's legal advocates to complete a legally enforceable plan. In the instance where no suitable kin can be found, it provides counseling and legal assistance in matching children with families who want to adopt. The agency continues to work with the guardian once the parents die, offering stabilization services and grief counseling to families, guardians and children.

Contact:

Living Legacy/Boston Pediatric and Family AIDS Center/Dimock Community Health Center
55 Dimock Street
Roxbury, MA 02119
(617) 442-8800
(617) 442-1702 - fax
www.dimock.org

Council on Adoptable Children, AIDS Orphans Adoption Program (New York, NY)

COAC's goal is to place as many children who are orphaned by AIDS as possible in permanent, loving, nurturing homes. A key component of the program is to identify HIV-infected parents who have no next of kin and who need assistance in finding adoptive parents. The staff counsels parents in making permanency plans for their children. An attorney is accessible to provide legal assistance and to facilitate the parent's plan. COAC also has a family support component that provides post placement psychological counseling for children and adults. The program recruits and trains parents who plan on adopting and wish to be guardians as well. Since its inception in 1993, the AIDS Orphan Program has assisted over 350 children to secure permanency.

Contact:

Council on Adoptable Children
589 Eighth Avenue, 15th Floor
New York, NY 10018
(212) 475-0222
(212) 714-2838 – fax
www.coac.org

The AIDS Resource Foundation for Children (Newark, NJ) The AIDS Resource Foundation for Children's Permanency Planning Project provides counseling, legal help, and linkages to services for parents living with HIV/AIDS. Case managers, the agency's consulting psychologist, and lawyers from Legal Services and other legal agencies work cooperatively with families on guardianship planning. Social workers provide counseling to parents and children in their homes, as well as at the agency's offices in Newark. When it is necessary to meet with a lawyer to petition the court for standby guardianship, draft wills or obtain legal counseling, the social worker arranges a meeting with the lawyer, the parent and the eventual guardian. Once the guardianship plans have been made, the family continues to receive support from the agency. Case managers link the family with services and help to obtain medical care. Counseling is also available to other family members. In addition, the agency provides a number of after-school programs and a family summer camp.

Contact:

AIDS Resource Foundation for Children
182 Roseville Avenue
Newark, NJ 07107
(973) 483-4250
www.aidsresource.org

Websites/On-line Resources

New York

GMHC Women and Family Services Department provides supportive services and counseling to assist families living with HIV/AIDS in navigating the different social and legal systems <http://www.gmhc.org/health/women/custody.html>

HIV/AIDS Services Administration (HASA) provides essential services and benefits to individuals and families with AIDS and advanced HIV illness. Their goal is to enable clients to manage the illness and live their lives with the fullest independence and dignity possible. http://www.nyc.gov/html/hra/html/serv_aids.html

The Family Center has extensive experience in developing programs for families affected by cancer, HIV/AIDS and other serious illnesses. The agency has been a pioneer in the research and design of services addressing permanency planning and disclosure. <http://www.thefamilycenter.org/>

The New York-Presbyterian System/SelectHealth is a Medicaid Special Needs Plan designed specifically for people living with HIV and their children who reside in the Bronx, Manhattan and Brooklyn. <http://nyps-selecthealth.intranets.com/login.asp>

National

The National Abandoned Infants Assistance Resource Center's mission is to enhance the quality of social and health services delivered to children who are abandoned or at-risk of abandonment due to the presence of drugs and/or HIV in the family. The Resource Center provides training, information, support, and resources to service providers who assist these children and their families. <http://aia.berkeley.edu/about/contact.html>

CASA (Court Appointed Special Advocates for Children) is a national on-line resource, with offices based in Washington State, of volunteers, organized state by state, appointed by a judge as Guardian ad Litem and empowered to advocate for children (whose parents may be unable to advocate personally) to help ensure that they don't get lost in an overburdened legal and social service system. <http://www.casenet.org>

Washington, D.C.

Family Ties Project's mission is to promote and preserve the well being of children, youth and families affected by HIV/AIDS by working with parents and caregivers to plan for the future care of their children. These objectives are accomplished through the direct collaborative efforts of a multi-disciplinary team of service providers, including case managers, therapists and attorneys. The project also advocates for policy changes to improve the life planning options available to parents and caregivers in Washington, DC.
<http://www.familytiesproject.org/>

Moving Forward, Next Steps, Conclusions

HIV/AIDS is arguably the most serious and complex health crisis of modern history – not only because of the staggering statistics relating to death rate and infection rate, nationally and worldwide, and the fact that scientific research has still been unable to discover a cure or vaccine – but also because many of the issues surrounding the response by society to the crisis directly connect to issues of racism, sexism and homophobia. In addition, these issues bring into sharp focus the inequalities of public health policies which are greatly skewed by the law, wealth and social status in addition to race, gender and sexual orientation (Stuntzner-Gibson, 1991). The following facts stand out as having perhaps the most significant implications informing areas that need to be addressed in policy and practice initiatives responding to HIV/AIDS and its effect on child welfare:

- The population most at risk for contracting HIV/AIDS, women of color, is underserved by the health care system (Cameron, 2000).
- Although new and more effective treatments have decreased death rates among women, and an increasing number of children born of HIV-positive mothers may not be HIV-positive themselves in years to come, this might mean that more children will live with mothers who are living with HIV illness (Van Loon, 2000; Crosson-Tower, 2004).
- HIV is still perceived as a demeaning disease of marginalized groups, adding HIV-related stigmas to existing experiences of being marginalized. This combination creates barriers to obtaining support and services (Poindexter and Linsk, 1999).

Recognizing the ways in which the public health crisis of HIV/AIDS is unlike other diseases points to the need to create expansive services particular to *this* disease and how it affects infected caregivers and their children. To be effective, these programs must provide a core of services in a multi-systems approach. Programs for children of terminally ill parents should provide assistance for the family during the parent's illness, including temporary care and custody for children while their parent is in the hospital or too ill to take care of their children; counseling and legal services to help the parent prepare for the death and make arrangements for children; and grief counseling services for children and families (Cameron, 2000; Andino, 2003).

Policies need to be enacted which create specific options for care for HIV-affected families, and give parents greater freedom to decide who will care for their children in the event of their death. One important possible policy initiative which can prevent some of the children affected by AIDS from becoming part of the child welfare system is for all state legislatures to pass standby guardianship laws, which can be put in place while parents are well and healthy without insisting upon them giving up any parental rights until and unless it becomes necessary.

On a federal policy level, an initiative such as the Early Treatment for HIV Act (ETHA), originally introduced before Congress in 1999, can have a direct effect in supporting family preservation. (Kaiser Family Foundation, 2003) This piece of legislation was re-introduced in April 2003 by Senators Gordon Smith (Republican/Oregon) and Hilary Rodham Clinton (Democrat/ New York), seeking to expand parameters of Medicaid eligibility. Current eligibility is narrowly defined to uninsured, low-income population groups of the disabled, parents and children, and the elderly. The purpose of the bill is to expand benefits to include coverage for low-income people by providing early, effective medical treatment upon the diagnosis of HIV infection rather than insisting on making people wait until they meet disability criterion, at which point they may be already too sick to take advantage of the health benefits of early medical intervention. Through the expansion of Medicaid coverage provided for by ETHA, uninsured, low-income, *non-disabled* individuals would be able to continue to work, earn money without the risk of being denied coverage for exceeding qualifying income level caps and still receive benefits. Legislation of this kind, acknowledging the link between human rights, societal responsibility and public health policy, seeks to challenge existing inequalities and change the reality that being poor is too often, literally, fatal.

Policies need to be adjusted which insist that parents be identified as "terminally ill" from HIV/AIDS, accompanied by societal stigmas that create barriers to seeking and receiving a variety of services which can help them stay physically and emotionally well for longer periods of time, while also recognizing the need to support parents *living* with disease, helping to keep HIV-affected families intact, for as long as possible.

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