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BOOK REVIEW

HIV ORPHANS: PROTECTING THE MOST VULNERABLE

*Abigail English**

A DEATH IN THE FAMILY: ORPHANS OF THE HIV EPIDEMIC,
Carol Levine ed., New York: Bantam Books (1993). 318 pp.

A Death in the Family: Orphans of the HIV Epidemic,¹ edited by Carol Levine, presents, in a poignant and provocative way, the newly emerging phenomenon of children and adolescents who are left behind when their parents, usually their mothers, die of HIV-related diseases or AIDS. This phenomenon is challenging the limits of service systems already severely overburdened by serious deterioration in the status of children. During the past decade, social, psychological and health problems have proliferated while the number of children living in poverty has increased. The problems confronting parents with HIV disease, their children, and their children's future caretakers raise critical legal and policy issues—such as concerns over child custody, foster care, public benefits and access to health care—that extend across the lines of social service, child welfare, mental health, medical and legal service systems. Providing both the personal and policy perspectives, Levine and her co-contributors effectively sound an alarm which we can ignore only at our peril.

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¹ A DEATH IN THE FAMILY: ORPHANS OF THE HIV EPIDEMIC (Carol Levine ed., 1993) [hereinafter A DEATH IN THE FAMILY].

THE SCOPE OF THE PROBLEM

In the book's most effective use of graphics, Michaëls and Levine provide a diagram of an iceberg to illustrate the proportion of children and adolescents affected by HIV/AIDS in various categories, including: AIDS cases in children and adolescents, HIV-infected children, uninfected siblings of HIV-infected children and adolescents, uninfected children whose parents are alive with HIV/AIDS, and uninfected children whose parents have died as a result of the virus.² According to a model they developed based on New York City data and applied to national figures, Michaels and Levine estimate that by the year 2000 more than 80,000 children and adolescents in the United States will be motherless as a result of the HIV epidemic.³ The authors' estimates dramatically draw attention to the scope of a problem that could easily go unnoticed except in the immediate circle of those affected.

The children most frequently highlighted by the media are the pediatric AIDS cases. As of September 1993,⁴ these cases totaled 4906, but represent only the tip of the iceberg in Michaels and Levine's diagram. This number remains relatively small in absolute terms because it does not reflect the number of HIV-infected children and adolescents who have not yet been diagnosed with AIDS. Moreover, it does not include the siblings of infected children and adolescents or uninfected orphans.

Not only is the problem larger in scope than often acknowledged by the public media, it may be of even greater magnitude than Michaels and Levine suggest. For example, they derive their estimates based on an assumption that the annual number of AIDS deaths will level off by 1995.⁵ Unfortunately, this is unlikely because the HIV epidemic is spreading so rapidly among women and girls, particularly those who are poor or members of racial and ethnic minority groups or

² David Michaels & Carol Levine, *The Youngest Survivors: Estimates of the Number of Motherless Youth Orphaned By AIDS in New York City*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 5.

³ *A DEATH IN THE FAMILY*, *supra* note 1, at 9.

⁴ Centers for Disease Control & Prevention, *HIV/AIDS SURVEILLANCE REP.*, Oct. 1993, at 5 (table 2).

⁵ *A DEATH IN THE FAMILY*, *supra* note 1, at 9.

both.⁶ Thus, the Michaels and Levine projections may well be on the conservative side. If so, the individual children, adolescents, parents and other caretakers affected by the growing "orphan" phenomenon could number in the hundreds of thousands in the very near future.

THE INDIVIDUAL VOICES

One of the most powerful aspects of *A Death in the Family* is the inclusion of personal stories told in the individual's own words. These individuals include the mother of a two-and-one-half-year old whose father died of AIDS, a 14-year-old New York City student whose father died of AIDS, a 16-year-old in the Midwest with an HIV-infected sibling, the grandmother of three HIV-infected children whose mother was also infected, the HIV-infected father of two adopted children, and an HIV-infected mother in the Bronx.⁷ The intimacy of these stories is more compelling than any statistics could be in evoking an empathetic understanding of the joy, sorrow, passion and pain in the lives of people, particularly the children and adolescents, affected by HIV/AIDS. As the 14-year-old daughter whose father died of AIDS said: "There are no words to describe how a person lives with a person who has AIDS."⁸ And yet these six individual stories successfully put into words the daily experiences which lay the foundation for the legal and policy issues that must be addressed to meet the urgent needs of these individuals and thousands of others like them.

THE LEGAL AND POLICY ISSUES

Both the statistical model and the individual stories presented in *A Death in the Family* raise critical legal and policy issues. These include issues in at least three major categories: child custody, guardianship and foster care; availability of public benefits and social services; and access to health care,

⁶ Catherine Teare & Abigail English, *Women, Girls, and the HIV Epidemic*, in *LOOKING FORWARD: A WOMEN'S HEALTH AGENDA FOR THE 21ST CENTURY* (Kary Moss ed., forthcoming 1994).

⁷ *A DEATH IN THE FAMILY*, *supra* note 1, at 36-52.

⁸ Michele S. Ramos, *The Two Worst Days*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 37.

including implications for health care reform. The authors explicitly address questions in the first two categories—such as who will care for the orphans and what support is available for them—and implicitly raise questions about how we can ensure that they will receive essential health care. The task of addressing these difficult legal and policy issues is not an easy one. As Michaels and Levine acknowledge:

Those who develop, interpret, and implement guidelines and programs of custody decisions, foster care, adoption, education, juvenile justice, health care, and institutionalization face a daunting challenge. They must find strength, flexibility, and creativity to address these urgent needs.⁹

They will only succeed in doing so if a legal framework exists which can be adapted to meet the needs of this population of children, adolescents, parents, family members and other caretakers.

CHILD CUSTODY, GUARDIANSHIP AND FOSTER CARE

The emotional and psychological issues associated with custody planning for children and adolescents who are likely to become AIDS orphans are numerous and weighty for both parents and children. These emotional and psychological concerns can only be dealt with effectively, however, if appropriate legal mechanisms are available to enable parents with HIV/AIDS to make decisions at a time and in a manner that is comfortable for them and that takes into account the specific characteristics of HIV/AIDS. For example, HIV-related diseases are sometimes manifested in episodic periods of acute illness, yet interspersed with much longer periods of relatively stable health during which a parent could reasonably expect to care for his or her children. However, current custody and caretaking arrangements for children—such as legal orders for custody, guardianship or adoption, as well as state-supervised foster care placements—generally are premised on the assumption that parents either are able to care for their children or are not.¹⁰ Moreover, the stigma associated with the disease dis-

⁹ Michaels & Levine, *supra* note 2, at 11.

¹⁰ Catherine Teare, *HIV/AIDS Orphans*, 15 YOUTH L. NEWS (forthcoming 1994).

courages both parents and children from addressing issues such as future planning in a forthright manner.¹¹ Legal protections of confidentiality often do not provide adequate protection either against disclosure itself¹² or against the multitude of other difficulties associated with disclosure, such as discrimination in access to health care and other services that HIV infected and affected individuals and families may encounter.¹³

A Death in the Family contains descriptions of some of the innovative approaches which have been implemented in New York to facilitate appropriate custody planning for HIV orphans. One option is a standby guardianship. This approach enables parents to select a guardian who can be appointed prior to the parent's death or incapacity without the parent having to relinquish control of the child before her health requires her to do so.¹⁴ An early permanency planning project allows parents who are expected to die within six months to be involved with the child welfare agency in selecting a foster parent for their children.¹⁵ In addition, a special project of the New York Legal Aid Society, based at Montefiore Medical Center in the Bronx provides legal services to people infected with HIV and has assisted HIV-infected parents in planning for their children's future by using wills, custody and guardianship proceedings, and standby guardianships.¹⁶ The availability of attorneys and advocates sensitive to the special needs of families affected by HIV can make a critical difference in successfully adapting a largely alien legal system to these families' needs. Levine and her co-contributors provide a valuable service by making the options described in the book

¹¹ *Id.* *A Death in the Family* also contains extremely poignant descriptions of the lengths to which both parents and children go to keep their HIV infection a secret and the pain and loneliness they experience in doing so. *A DEATH IN THE FAMILY*, *supra* note 1, at 16-19, 69-74.

¹² See, e.g., Abigail English, *The HIV-AIDS Epidemic and the Child Welfare System: Protecting the Rights of Infants, Young Children and Adolescents*, 77 IOWA L. REV. 1509, 1537-38 (1992).

¹³ *A DEATH IN THE FAMILY*, *supra* note 1, at 73.

¹⁴ Alice Herb, *The New York State Standby Guardianship Law: A New Option for Terminally Ill Parents*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 87-93.

¹⁵ Regina J. Prince, *The Child Welfare Administration's Early Permanency Planning Project*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 110-17.

¹⁶ Mildred Pinott, *Custody and Placement: The Legal Issues*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 75-84.

known to a wider audience—including HIV-affected families and their advocates outside New York.

BENEFITS

HIV orphans and families affected by HIV need a multitude of services which extend across the boundaries of numerous systems—child welfare, health care, mental health, juvenile justice, education, public welfare and others. The availability of services and financial benefits through these systems depends upon a complex set of overlapping, interrelated, and sometimes conflicting statutory and regulatory requirements which govern eligibility, scope of benefits and due process procedures. Often these requirements do not facilitate—or actually impede—the delivery of appropriate services or the provision of essential financial support to HIV orphans and their families.

The way in which eligibility requirements and benefit rules can limit access to essential support is illustrated by the statutory and regulatory scheme establishing the framework for foster care benefits.¹⁷ Children who meet eligibility criteria for federal foster care maintenance payments available under Title IV-E of the Social Security Act may receive those payments even if they are placed with foster parents who are related to them.¹⁸ Children who do not meet the federal criteria may be eligible for foster care payments under state-funded programs. However, many states have chosen not to provide foster care payments under their state-funded programs for children living with relatives.¹⁹ For many HIV orphans, placement with a relative would be the most appropriate care arrangement, but some of these children would not meet all of the federal IV-E eligibility requirements. These families are either forced to choose between providing a home for the children while receiving a lower level of financial support (which might be available under the regular AFDC program)²⁰ or

¹⁷ See Teare, *supra* note 10.

¹⁸ See *Miller v. Youakim*, 440 U.S. 125, 145 (1979); see also English, *supra* note 12, at 1549-50, 1549 n.212.

¹⁹ English, *supra* note 12, at 1549-50, 1550 nn.213-15.

²⁰ See *King v. McMahon*, 230 Cal. Rptr. 911, 913-14, 913 n.7 (Ct. App. 1986) (explaining that foster children living with related foster parents can receive benefits under the regular AFDC program).

sending the children to live with strangers in whose home they might qualify for higher financial benefits. Such choices are the direct result of anomalies in existing law and add complexity to the already difficult decisions HIV-infected parents face. Moreover, they deprive those children of either the financial or familial support they need.

IMPLICATIONS FOR HEALTH CARE REFORM

A Death in the Family is liberally seeded with recommendations of services that HIV orphans, their parents, other family members and caretakers need. Many of these services are medical or health-related since all of the parents are HIV-infected themselves, and many of the children and adolescents are either already infected with the virus or at serious risk for infection.²¹ These parents and children alike need access both to primary health care services and to more specialized HIV care.²² In addition, the high rates of depression and other mental health problems identified in adolescents living in families with AIDS suggest that access to a broad range of mental health services is essential for those adolescents,²³ as well as other family members.

Although not discussed in the book, implementation of the recommendations for expanded availability of medical care and health-related services will depend largely on the outcome of the current health care reform debate both at the state and federal levels. In order for any health care reform proposal to meet the needs of children and adolescents generally a number of goals must be achieved.²⁴ Moreover, the needs of HIV or-

²¹ An anonymous survey of well adolescents in families with AIDS revealed that while many of the adolescents understood the dangers of drugs and AIDS, few had "heeded the message" about unprotected sex. Barbara Draimin, *Adolescents in Families with AIDS: Growing Up with Loss*, in *A DEATH IN THE FAMILY*, *supra* note 1, at 15.

²² Teare & English, *supra* note 6.

²³ *A DEATH IN THE FAMILY*, *supra* note 1, at 14.

²⁴ Jane Perkins & Abigail English, *Evaluating Health Reform Proposals in the Interest of Children and Adolescents*, 27 CLEARINGHOUSE REV. 428 (1993) (proposing ten benchmarks: universal coverage; simplicity of enrollment; portability; effective coverage for children living apart from their families; comprehensive benefits; affordable cost sharing; protections against discrimination; service to medically underserved areas and populations; protections in managed care; and due process).

phans, whether HIV-infected or not, are likely to be even more demanding than those of other children and adolescents. Providing essential health care services to these special populations is an especially great challenge²⁵ and one which any new health care reform legislation will meet only through the dedicated efforts of advocates such as Levine and her co-contributors.

CONCLUSION

The system (or non-system) of services which should meet the needs of HIV-affected families is characterized by a broad range of legal requirements which frequently impede appropriate delivery of services. As Levine recognizes, the inadequacies of the services, and of the statutory and regulatory provisions which control them, extend beyond the unmet needs of HIV-affected families to all other families whose problems are associated with poverty, child abuse, urban decay and other societal crises.²⁶ A successful attempt to meet the needs of HIV-affected families, including HIV orphans, will ultimately require a broader effort to address the problems of vulnerable children and families generally. As Levine suggests, perhaps the plight of HIV orphans, with their extraordinary vulnerability, will serve as a catalyst for society to undertake tasks which would be essential even absent the HIV epidemic.

²⁵ E.g., Abigail English, *Adolescents and Health Care Reform: Protecting Special Populations*, 15 YOUTH L. NEWS 14 (1994); Abigail English & Jane Perkins, *Health Care Reform: Protecting Vulnerable Children* (Apr. 22, 1994) (paper presented at the ABA Conference on Children and the Law, Washington, D.C.) (on file with the *Brooklyn Law Review*).

²⁶ A DEATH IN THE FAMILY, *supra* note 1, at xiii; see also English, *supra* note 12, at 1517 (suggesting that to the extent that child welfare agencies focus special attention on children with HIV infection, they should do so in a manner designed to improve delivery of services to other children with special medical needs and to all children).