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Developments in Custody Options for HIV-Positive Parents

Sunny Rosenfeldt†

I. Case Study1

Like most mothers, Deborah never imagined she would have to worry about a time when she would not be able to care for her children. Her husband, Jim, passed away two years ago from AIDS, and now Deborah is beginning to face the harsh reality that she will not have much longer with her children. This winter, pneumonia kept Deborah in the hospital for two weeks. She has lost twenty pounds in the last six months. Fatigue often keeps her in bed, and her T-cell count is now at forty. Deborah has come to realize that planning for her children’s future custody cannot be put off any longer.

When Jim became too ill to work, Deborah had to quit her job to care for him. With both incomes gone and their savings spent on medication, they had no choice but to move in with family and accept government aid. Deborah receives Supplemental Security Income (“SSI”), and her children receive Social Security Survivor Benefits, as well as SSI for their emotional and developmental needs. Medi-Cal pays for health care, and food stamps pay for some necessities, but after rent, heat, and water are paid, not much is left over for such “luxuries” as toys and books for the children. Deborah and her children are now living in public housing, and though Deborah worries about the local drug dealers and the neighborhood school’s dropout rate, she feels lucky to have finally gotten housing after a year and a half wait.

Deborah’s sister helps with the children, walking them to school in the morning and preparing dinner in the evening, but she lacks legal authority to meet many of the children’s needs. Doctors and counselors will not allow her to consent to the children’s medical and psychological care, even

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1 “Deborah” does not refer to a specific person but instead represents a composite of the clients with whom the author worked at Berkeley Community Law Center’s HIV/AIDS project. The feminine form is often used in this article because of the great impact that HIV has on single mothers. All parents, however, can avail themselves of the provisions referred to within.
when Deborah is unable to. The children’s school will not allow her to sign releases for field trips or attend the bi-yearly educational planning meetings that are held for each child with special needs.

If Deborah cannot get the assistance she needs, she may have to give up custody of her children while she is still able, in many ways, to be “mom.” She is afraid that if she does not relinquish custody of her children now, she may lose her chance to select their future custodian. Deborah worries that the children will be placed in the foster care system, where they risk being separated from each other and bounced from home to home. She worries that her testamentary wishes will not be honored and that the children’s paternal grandparents will try to obtain custody of the children after she passes away—something neither she nor the children want.

II. Introduction

As the rate of AIDS among women increases, Deborah's story is becoming more and more common: Illness begets poverty, inadequate housing, and an unstable future for the surviving children. Statistics indicate that the rate of AIDS among women is rapidly increasing. Females constitute 11% of all adults with AIDS but 29% of all adolescents.2 Seventy-two percent of adolescent girls with AIDS are African-American or Latina.3 A survey of HIV-positive mothers in Chicago found that 80% are the sole caretakers of their children, most have a history of substance abuse, and the majority are supported by public assistance.4

Nationwide statistics predict that by the year 2000, HIV-positive women will have given birth to between 80,000 and 100,000 HIV-negative children and between 32,000 and 38,000 HIV-positive children.5 Of all children born HIV-positive in the United States, 54% are African-American and 24% are Latina, even though these groups respectively constitute only 14% and 11% of all children in the nation.6 The overwhelming majority of these children live in households that are below the poverty line.7 Not sur-

3 Id.
prisingly, they are at high risk for a variety of emotional and behavioral problems. When considering that the grief and loss these children experience upon the death of a parent is compounded by poverty, the tremendous difficulties they face become painfully evident.

One of the most pressing concerns faced by every HIV-positive parent is that her children are taken care of during her illness and after her death by an individual of her choice. The purpose of this paper is to identify the options available to the growing number of terminally ill parents and articulate the strengths and weaknesses of these options.

III. Discussion

Deborah’s desire to retain custody of her children until the very end of her life is common. However, it is not easy; her options are limited. Many parents have been forced to relinquish permanent custody of their children during periods of illness, though their inability to care for them may be only partial or temporary. These children are often adopted or placed in foster care or with a legal guardian. Other parents make informal arrangements with friends or family members and make their future custody wishes known through wills, but these are less secure arrangements.

While some HIV-positive parents establish future custody arrangements for their children, many do not. Their inability to plan may be due to denial, fear of disclosure, the lack of a potential guardian, a lack of counseling or legal advice, or inflexible laws. In 1989, 39% of HIV-positive children born at Harlem Hospital went into foster care directly from the newborn nursery because of their mothers’ inability to provide them with adequate care. These children have a range of psychological, educational, and health needs that are unmet by an already overburdened and underfunded foster care system.

Despite the early loss of their children, terminally ill parents often regard legal guardianship as the most stable and permanent custody arrangement for their children because it avoids placing the children in foster care and allows the parent to choose the children’s caretaker. A legal guardian is granted legal and physical custody of the child, giving her the legal authority to act in the child’s best interest. Many experts believe that children who are separated from their parents are better off remaining with relatives or close family friends than being placed in unfamiliar foster care.

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9 Telephone Interview with Jean Lewis, Staff Attorney at Legal Services for Children’s HOPE Project (Feb. 10, 1996).
10 Id.
13 CAL. PROB. CODE §§ 2108, 2351(a) (West Supp. 1995).
families or group homes. Those children who do enter the foster care system may be moved through a series of homes where they cannot develop permanent relationships with their caregivers. By choosing to provide their children with a legal guardian, parents can reduce the trauma children experience at being separated from their parents, enhance the children’s opportunities to stay connected to their own communities, and increase their chances of growing up with their siblings.

Many parents with AIDS, however, do not want to relinquish custody of their children to a legal guardian, because it deprives them of physical custody of their children while they are still periodically able to care for them. Many resort to less formal but more insecure arrangements that allow them to retain legal custody of their children until their death. But expressing their wishes for the children’s future custody in a will or verbally to family and friends is often inadequate. Parents must trust that their wishes regarding the future custody of their children will be honored. Moreover, caregivers are without legal authority to make important decisions about medical care and schooling or to receive public assistance on the children’s behalf while the parent is still alive.

IV. STANDBY AND JOINT GUARDIANSHIP

Several states have begun to legislate solutions aimed at allowing parents the opportunity to make plans for their children’s future without relinquishing custody. Standby and joint guardianships allow parents to take an active part in choosing a future home for their children and help ease the transition between caregivers. Standby guardianship laws are currently in effect in Connecticut, Florida, Illinois, Maryland, New Jersey, New York, and North Carolina, while joint guardianship is available in California.

Standby guardianship enables a parent suffering from a progressive, terminal disease to appoint a guardian to step in upon the parent’s incapacitation or death and assume responsibility for her children. The proposed guardian “stands by” until a specific event occurs that triggers her legal

17 CAL. PROB. CODE § 2105(f) (West Supp. 1995).
18 See, e.g., FLA. STAT. ANN. § 744.304(3) (West Supp. 1996) (providing that “The standby guardian . . . shall be empowered to assume the duties of his office immediately on the death or adjudication of incapacity of the last surviving natural or adoptive parent of a minor . . . .”).
The triggering event may become a point of dispute if a parent does not feel ready to give up her rights at that time. The National Standby Guardianship Act, introduced January 26, 1995 by Congresswoman Carolyn Maloney (D-NY), would require states to amend court procedures and close legal gaps so that chronically ill parents could choose standby guardians for their children without giving up parental rights. If passed into law, the Standby Guardianship Act would amend Part E of Title IV of the Social Security Act. The bill has been referred to the House Ways and Means Committee.

In October of 1993, California Governor Pete Wilson signed a joint guardianship law that allows terminally ill parents to appoint a legal guardian with whom they share equal parental rights and responsibilities. The joint guardianship remains effective until the parent’s death, at which time the joint guardian assumes sole responsibility. The statute was amended to remove a requirement that the parent’s condition, “within reasonable medical judgment, result in death within two years.” The removal of the “sick enough” requirement took effect on January 1, 1996. Under joint or regular guardianship, a court must find that the custody plan is “necessary or convenient” for the child, and that the guardianship is in the child’s “best interest.”

California’s joint guardianship law solves many of the problems which have arisen under guardianship and standby guardianship laws. It particularly suits the episodic nature of AIDS, as it empowers the joint guardian to assume the child’s care during periods of the parent’s incapacitation while allowing the parent to resume care when she is able. The parent and joint guardian are each legally and psychologically positioned to care for the child until the parent’s death. This helps prevent the disputes that arise under standby guardianship over the exact point at which the parent is incapacitated and custody should transfer to the guardian. Another benefit of shared custody is the involvement of the joint guardian in the child’s life before his or her parent’s death. This makes the child’s transition smoother during periods of the parent’s incapacitation and at the time of the parent’s

19 Id.
22 Id.
23 Id.
27 Id.
28 CAL. PROB. CODE § 1514(a), (e)(1) (West Supp. 1995).
29 Telephone Interview with Jean Lewis, supra note 9.
death. Additionally, it eases the stress of an ailing parent who cannot be her children’s sole, full-time caregiver.

Joint guardianship is not without its problems. Because parent and joint guardian share custody equally, they must resolve any disputes they have over the child’s care together. The new law is silent on how to resolve such disputes. A parent can attempt to avoid this problem by choosing a joint guardian that the child likes, is presently involved in the child’s life, understands the child’s particular needs, lives nearby, and with whom the parent has good communication. But for many parents this ideal co-parent does not exist. Without more permanency planning agencies to join terminally ill parents with potential guardians, joint guardianship is not a viable option for many families. Often a standby guardian feels safer to a parent who does not want to make child-rearing decisions with another person but wants to formalize that person’s relationship as the child’s future caregiver.

Although an additional child can be a great financial burden to many families, Aid to Families with Dependent Children (“AFDC”) is available in California to guardians and joint guardians once they have assumed the primary care of the child. However, anticipated congressional budget cuts threaten to reduce or even eliminate funding for AFDC. General cuts to welfare, housing, and health care may further discourage potential guardians from becoming caregivers.

Standby and joint guardianship are relatively new. As a result, many parents and people who work with HIV-positive populations are unaware of the options available in their state. Few attorneys know of these options or have experience in the procedures involved. Additionally, there is little financial incentive for attorneys to learn these skills, because many HIV-positive parents cannot afford their fees. Consequently, few terminally ill parents have been able to avail themselves of these options.

V. Conclusion

Although progress has been made in developing custody options that meet the needs of HIV-affected families, there are still financial, emotional, and logistical impediments to early planning. As more states begin to address the need of HIV-positive parents to plan for the future care of their children, they should consider standby and joint guardianship, as well as other forms of permanency planning, but not to the exclusion of other options. Parents must be able to choose the option that best fits their particular family’s needs.

30 CAL. PROB. CODE § 2105(c)(1) (West Supp. 1995).
31 CAL. WELF. & INST. CODE § 11405(a) (West Supp. 1995).