REPRESENTING FAMILIES AFFECTED BY HIV/AIDS: HOW THE PROPOSED FEDERAL STANDBY GUARDIANSHIP ACT FACILITATES FUTURE PLANNING IN THE BEST INTERESTS OF THE CHILD AND FAMILY

KELLY C. ROZMUS*

I. INTRODUCTION .......................................................................................... 300

II. LEGAL BENEFITS OF THE PROPOSED FEDERAL STANDBY GUARDIANSHIP ACT: THE NATIONAL NEED ..................................................... 302

A. A Comparison of the Traditional Options: Wills, Custody Proceedings, Guardianships and Foster Care .............................................................. 302
   1. Wills ............................................................................................... 303
   2. Custody Proceedings ........................................................................ 303
   3. Guardianships ................................................................................ 304
   4. Foster Care ................................................................................... 306

B. A Non-Legal Approach: The Dangers of Informal Guardianship Arrangements ......................................................................................... 308

C. A New Alternative for Mothers with HIV/AIDS: The Federal Standby Guardianship Act ........................................................................... 309
   1. The Proposed Statute ................................................................. 309
   2. A Comparison of Existing State Statutes: California's Joint Guardianship Law and Standby Guardianship Laws ........................................ 310

III. THE PROPOSED FEDERAL STANDBY GUARDIANSHIP ACT ENHANCES POSITIVE OUTCOMES FOR THE CHILD ......................................... 316

A. How the Proposed Federal Standby Guardianship Act Facilitates a Smooth Outcome for Children Orphaned By AIDS ....................................... 316
   1. The Proposed Federal Standby Guardianship Act Provides "Shared Time" .................................................................................................................... 316
   2. The Proposed Federal Standby Guardianship Act Accommodates the Need to Keep Siblings Together ............................................................ 317

* J.D., UCLA School of Law, 1997, B.S. University of Wisconsin, School of Education, 1991. I would like to thank Virginia Weisz, Directing Attorney of Public Counsel's Children's Rights Project for her dedication and insights, Prof. Robert Goldstein for his suggestions, Geri Gehl for her technical assistance and support, and the staff of the Journal of Gender and the Law for their editorial contributions.
I. INTRODUCTION

As the Acquired Immune Deficiency Syndrome (AIDS) epidemic enters into its second decade, women are the fastest growing segment of the disease's victims. The National Institute of Allergy and Infectious Diseases (NIAID) ranked AIDS as the fourth leading cause of death for American women aged 25 to 44.1 In fifteen major U.S. cities, AIDS is the number one cause of death for women in this age range.2 Unfortunately, because women in this age range often have children and HIV/AIDS symptoms typically manifest after extended periods of time, it is not surprising that many of the women diagnosed with HIV/AIDS are mothers, often single parents, who had not even known they had contracted HIV/AIDS.3 In many cases, declining health is just one obstacle to helping these mothers and their families.4 The AIDS Clinical Trials Group found that many women

1. NATIONAL INSTITUTE OF ALLERGY & INFECTIOUS DISEASES, U.S. DEP'T OF HEALTH & HUMAN RESOURCES 2 (1995) [hereinafter NIAID Report] (reporting that approximately 48% of women in the United States contracted AIDS by sharing needles with HIV-infected drug users and that AIDS contracted by heterosexual contact rose to over 36% of all cases). See Andrew Purvis, The Global Epidemic, TIME, Jan. 6, 1997, at 76 (reporting that 20% of the 750,000 people living with HIV/AIDS in North America are women); see also Facts About AIDS, OPTIMIST 6 (1997) (estimating that through the year 1996, of the 29.4 million people living with HIV/AIDS, 75% of those afflicted with HIV/AIDS were infected through heterosexual sex).

2. NIAID Report, supra note 1, at 1. See supra note 1, at 6 (stating that one out of every 250 people in the United States is infected with HIV/AIDS; every 15 minutes someone dies an AIDS-related death in the United States).


The changes in the AIDS epidemic mimic the course of other epidemics: infections quickly spread through the population groups who are first affected or those who are most at risk... In the United States transmission among heterosexual partners represents the second wave of the epidemic... Already, more children in this country lose their mothers each year to AIDS than to automobile accidents. By 1990, AIDS was the leading cause of death of young women in nine large cities.


4. For example, the Center on Hunger, Poverty and Nutrition Policy reported that most poverty is attributable "mainly to changes in labor markets and the structure of the economy, which made it increasingly difficult for both married and single parents to maintain or improve
with HIV lack access to appropriate health care and to alternatives to support their families. Up to 40% of their children may be infected with HIV/AIDS, which could take years to diagnose because of the dormant characteristics of the virus.

When parents die from AIDS, their children may find some support in health, social, and psychological services. Without a Standby Guardianship Act, however, families affected by HIV/AIDS lack an effective tool for providing for their children’s future care. The Act would reduce the number of children left in legal limbo by creating procedures and laws permitting parents who are dying to designate a standby guardian upon their death, without requiring those parents to surrender their parental rights before they die. In recognition of these problems, several Congresspersons proposed a bill that would amend Part E of the Social Security Act of Title IV, to include a Standby Guardianship Act.

This Article will discuss legal and social issues regarding the enactment of a national Standby Guardianship Act. Part I reviews the traditional options for mothers with HIV/AIDS and describes the Act's their economic status.” CENTER ON HUNGER, POVERTY AND NUTRITION POLICY, STATEMENT ON KEY WELFARE REFORM ISSUES: THE EMPirical EVIDENCE 10 (1995). The Center also noted that the Census Bureau found 85% of child poverty could be traced to low paying jobs and other economic factors. Id. Unable to find living-wage work, mothers with HIV/AIDS become destined to a life of poverty as well as disease. See Alan Lupo, Don't Let Facts Spoil the Welfare Debate, BOSTON GLOBE, Feb. 19, 1995, at 2 (describing the Center’s report and arguments surrounding it); Michael M. Burns, Fearing the Mirror: Responding to Beggars in a "Kinder and Gentler" America, 19 HASTINGS CONST. L.Q. 783, 801 (1992) (noting that many working poor and unemployed “decline to enroll for welfare and entitlement programs, preferring to fend for themselves on the streets,” rather than facing the shame and humiliation of becoming dependent on the government); Shelley Geballe, Toward a Child-Responsive Legal System, FORGOTTEN CHILDREN, supra note 3, at 152 (observing that the health needs of many children and youths whose parents are dying of AIDS “have[e] been subordinated to the health needs of ill family members”).

5. NIAID Report, supra note 1, at 5. The AIDS Clinical Trials Group (ACTG) is a network of research center sites at fifty-seven major academic institutions. Id. at 4. See also Richard Lacayo, Hope With an Asterisk, TIME, Jan. 6, 1997, at 84 (quoting Gary Cohan, a Los Angeles AIDS specialist, as saying that recent treatment breakthroughs are cost-prohibitive for many HIV/AIDS patients in the United States, about one half of whom qualify for Medicaid, making AIDS “a two-world disease: The wealthy vs. the indigent”).

6. NIAID Report, supra note 1, at 6.


8. Original congressional co-sponsors for the Standby Guardianship Act amendment to Part E of Title IV of the Social Security Act include Maloney (D-NY, lead sponsor), Deutsch (D-FL), Evans (D-IL), McDermott (D-WA), Miller (D-CA), Schumer (D-NY), and Studds (D-MA). Added sponsors include Clayton (D-NC), DeLauro (D-CT), Engel (D-NY), Fattah (D-PA), Frost (D-TX), Hinchey (D-PA), Holden (D-MA), Jackson-Lee (D-TX), Masui (D-CA), Morella (R-MD), Pelosi (D-CA), Rangel (D-NY), Solomon (R-NY), Dellums (D-CA), Moran (D-VA), Waxman (D-CA), Johnson, E.B. (D-TX), Lowey (D-NY), McKinney (D-CA), Nadler (D-NY), Parker (R-MS), Romero-Barcelo (D-PR), Sarbanes (D-MD), Stupak (D-CA), and Velazquez (D-PA). 143 CONG. REC. H2012-06, H2033 (1997).


10. Although mothers tend to be the last living parent in families affected with HIV/AIDS,
advantages over traditional options and the dangers of designating a caregiver without a court’s endorsement. Two current statutes, California’s Joint Guardianship Law and New York’s Standby Guardianship Law, will also be compared. Part II demonstrates how, by implementing such guardianship laws, a smooth transition to a new family situation can be accomplished. This discussion examines how the law considers the social as well as legal needs of interested parties: the children, parents, potential guardians, and social workers and case managers. Finally, the Conclusion emphasizes the need for a federal Standby Guardianship Act. The Act would uniformly enable terminally ill parents to act in the best interests of their children, empowering parents to ensure their children’s social and legal welfare while they still can.

II. LEGAL BENEFITS OF THE PROPOSED FEDERAL STANDBY GUARDIANSHIP ACT: THE NATIONAL NEED

In a termination of parental rights proceeding that resulted from alleged child neglect, a mother with HIV testified that her cousin would care for her children after she died from AIDS. When pressed about her current situation, “[the mother] gave no real plan other than to say that she [the mother] and the kids will get a place and she will find another job.” As the mother had made no effort to prepare for her children’s future using traditional legal alternatives such as a will, custody transfer, guardianship, or voluntary placement through the foster care system, the court disregarded her wishes regarding her children’s caretakers after her death. The court neither presented nor considered any possible alternatives and Delaware, where this case was litigated, does not yet have a Standby Guardianship Law.

A. A Comparison of the Traditional Options: Wills, Custody Proceedings, Guardianships and Foster Care

For many mothers with AIDS, there are no satisfactory opportunities to legally plan for their children’s future care among the traditional options. The wills, custody proceedings, and guardianship proceedings are not real alternatives because these options either leave open the question of whether the parent’s choice of guardian

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12. *Id.*
13. *Id.*
will be approved or force the parent to relinquish parental rights before her death or incapacitation.

1. **Wills**

A last will and testament allows the mother to retain her guardianship rights until her death, but are only documents, and do not guarantee that her nominated guardian will become so. For instance, one parent’s wishes do not override the other’s; therefore, a non-custodial, long absent parent’s legal rights are untouched by a will. Even if uncontested, the court determines who gains guardianship under the “best interest of the child” standard and the investigations required to make this determination usually take three to four months. During probate investigations, a child may be placed with the prospective guardian, with another relative, or as a ward of the State.

2. **Custody Proceedings**

Custody proceedings are another legal option for the disposition of parental guardianship when a parent is ill. In California, the transfer of custodial rights occurs only between parents; the transfer to a non-parent is part of a guardianship proceeding. This differs from New York, for example, where parents can jointly transfer custodial

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15. *See*, e.g., Stanley v. Illinois, 405 U.S. 645, 649-58 (1972) (stating that the State cannot, consistently with due process requirements, merely presume that unmarried fathers in general and petitioner in particular are unsuitable and neglectful parents and that parental unfitness must be established on the basis of individual proof).

16. *See*, e.g., CAL. FAM. CODE § 3011 (West 1997) (describing factors to consider when determining the best interest of the child); Pinott, *supra* note 14, at 78.


18. For example, *see* CAL. FAM. CODE § 3022 (West 1997) (“The court may, during the pendency of a proceeding or at any time thereafter, make an order for the custody of a child during minority that seems necessary or proper.”) (emphasis added). Several other statutory provisions establish a court’s authority to place the child without explicitly directing the court how to place the child. For instance, under the Family Code, a general hierarchy of placement is outlined but not prescribed. *Id.* § 3041 (requiring that “[b]efore making an order granting custody to a person or persons other than a parent, without the consent of the parents, the court shall make a finding that granting custody to a parent would be detrimental to the child and that granting custody to the nonparent is required to serve the best interest of the child”). An abused or neglected child is under the court’s jurisdiction and can be removed to the most expedient placement available in order to protect the child. *See*, e.g., CAL. WELF. & INST. CODE § 300 (West 1997) (stating that a parent may lose their child to the State where the child is found to be physically or sexually abused, neglected, or emotionally damaged); *id.* § 360 (West 1997) (explaining that the court may appoint a legal guardian if the parent has advised the court that they are not interested in “family maintenance” and it is in the child’s “best interest”); *id.* § 361.5 (stating that the parent may lose their child to the State if shown by medical experts to be mentally unable to care for the child).
rights. Custody consists of two parts: legal custody, which is holding the right and responsibility to raise the child; and physical custody, which is providing a home and holding actual physical custody of the child. The essence of child custody includes companionship of the child as well as the power to make decisions regarding the child's care, control, education, health, and religious upbringing. In New York, as well as in other jurisdictions, a custody proceeding is especially suitable for surviving single parents or two-parent families where both are ill. The transfer of custody in states with laws similar to California requires the consent of both living parents. Where parents agree on the custodial nominee, custody proceedings transfer the rights to make daily decisions and to physically care for the child to that nominee, but the mother and father retain parental rights. In New York, a guardianship proceeding must also follow the death of the parent(s) to establish the custodial adult as the legal guardian, along with the proceeding's lengthy probate investigation and uncertain outcome.

3. Guardianships

Traditional guardianships transfer parental rights to a non-parent, as opposed to a parent who could potentially win custody. A relative, other adult, or a minor over the age of twelve can file a petition to appoint a guardian of a minor. A guardian is a person who is entrusted with the "care, custody, control, and education" of the child. California courts appoint guardians only where they appear "necessary and convenient." A court must also consider the child's best interests, the nominated guardian's "concern for and interest in the welfare" of the child, and the child's preference. Parents can initi-
ate the guardianship proceedings, but each parent must consent to the transfer of guardianship. Custody is changed more easily than guardianship because natural parents, not guardians, have a “fundamental liberty interest... in the care, custody, and management of their child.”

Once guardianship proceedings are completed, although they no longer possess parental rights, many mothers with AIDS continue to live with and care for their children through an informal arrangement with the legal guardian. After a guardian is appointed, the parent must at least in form give up parental rights; this can be especially painful because, typically, the parent who initiates a guardianship proceeding is still able to care for her children. In California, a parent who transfers guardianship loses certain parental rights, such as the right to choose where the child will live, how the child will be

30. See CAL. PROB. CODE § 1510(a) (West 1997) (stating that a relative may file a petition for the appointment of a guardian for the minor); see also Santowsky v. Kramer, 455 U.S. 745 (1992) (stating that there is a fundamental liberty interest of natural parents in the care, custody, and management of their child).

31. See CAL. PROB. CODE § 2105(f) (West 1997) (stating that a non-custodial parent can prevent a custodial parent and/or a person designated by custodial parent from becoming joint guardians of a minor, unless the non-custodial parent's custody would be detrimental to the minor); see, e.g., CAL. FAM. CODE § 3041 (West 1997) (stating that for custody to be granted to a non-parent, unless both parents give consent, the court must make a finding that granting custody to a parent would be detrimental to the child); id. § 3020(b) (West Supp. 1997) (declaring that, as a matter of public policy, the State encourages both parents to have frequent and continuing contact with their children after separation, and to share the rights and responsibilities of child rearing); Stanley v. Illinois, 405 U.S. 645 (1972) (ruling that an unwed father was entitled to a hearing on his fitness as a parent before his children could be taken from him in a dependency proceeding); Lusker v. Guardianship of Bena Christine Lusker, 434 So. 2d 951, 953 (Fla. Dist. Ct. App. 1983) (stating that even if one parent has been granted custody, both parents must join in a petition for the appointment of a standby guardian); supra notes 178-81 and accompanying text.

32. See, e.g., Stanley, 405 U.S. at 645 (finding that if parents are the parties in a custodial dispute, courts presume both parents are able to care for the child unless there is a showing that the parent is unfit and it is in the child’s best interests to live with another adult); see also CAL. PROB. CODE § 1514(e) (West 1997) (observing that, in a guardianship proceeding, a court must examine the proposed guardian’s “concern for and interest in the welfare of the proposed ward,” and also must consider the child’s wishes where the child can make an “intelligent preference”). But see CAL. FAM. CODE § 3011 (West 1997) (noting that these considerations are not mentioned in the California Family Code Section which deals with the factors a court should use to determine the best interest of a child in a custody proceeding).

33. Pinott, supra note 14, at 80.

34. See Symposium, Comments by Marina T. Sarmiento: The Legal Needs of Women with HIV, 9 BERKELEY WOMEN'S L.J. 155, 159 (1994). While this strategy is slightly better than designating a guardian by will, where the parent is unable to advocate for her choice, the court is still not required to grant the mother’s wish of new guardian and the court will order that the new guardian assume the role of parent upon appointment. There is no documentation to suggest that courts will enforce an arrangement where the parent and guardian informally agree to allow the parent to continue caregiving. However, where the parent and guardian do not agree on an issue of child raising, the guardian, by law, will trump the parent. See also Geballe, supra note 4, at 149.
cared for, and what type of education the child will receive.\textsuperscript{35} Although this legal option provides some certainty about the child's future caregiver, guardianships require a mother with AIDS to transfer her custodial rights and potentially lose opportunities to make important decisions about her child.

4. Foster Care

Foster care furnishes another means of caring for the children of mothers with HIV/AIDS. The foster care system provides a short-term, familial placement for eligible children. In California, children enter the foster care system through two avenues: wardship proceedings and dependency proceedings.\textsuperscript{36} Wardship proceedings follow the arrest of the child and provide the juvenile court with jurisdiction over the child.\textsuperscript{37} In contrast, a private individual or the Department of Children Services (DCS) can initiate a dependency proceeding.\textsuperscript{38} After an individual's petition or DCS's preliminary investigation, a court determines whether there is a substantial risk that the child will suffer serious harm, illness, or abuse if the child remains with the parent or legal guardian.\textsuperscript{39} If the court deems the child dependent, the court may place the child in foster care and will review the child's case no less frequently than once every six months.\textsuperscript{40} Routine permanency planning follows this review until the child is adopted, placed with a relative or in long-term foster care, or emancipated.\textsuperscript{41} This process, however, does not provide much stability or certainty in the child's care. In California, and most states, foster care is supposed to be a temporary solution for parents who cannot care for their children, because it is considered less preferable than more permanent plans for children such as the adoption or appointment of a legal guardian.\textsuperscript{42} To "ensure that children are given a chance to have a

\textsuperscript{35} See CAL. PROB. CODE §§ 2351, 2352 (West 1997).
\textsuperscript{36} See LEGAL AID FOUNDATION OF LOS ANGELES, GOVERNMENT BENEFITS UNIT, THE FOSTER CARE MANUAL 4 (1993) [hereinafter LAFLA].
\textsuperscript{37} See CAL. WELF. & INST. CODE § 602 (West 1997).
\textsuperscript{38} See id. §§ 300, 329 (West 1997).
\textsuperscript{39} See id. § 300 (West 1997).
\textsuperscript{40} See id. § 366 (West 1997); see also LAFLA, supra note 36, at 6 (noting that after the court assumes jurisdiction over the child, usually granted shortly after a report of abuse/neglect is filed by the Department of Social Services, there is a detention hearing if the child was taken from home without a court order. This must occur within one working day of detention. Next, a pre-adjudication hearing is held for the parent and child to state their stories and work with a social worker toward resolving problems, and, if the latter is unsuccessful, an adjudication hearing is held where the court determines whether the allegations against the parent are true).
\textsuperscript{41} LAFLA, supra note 36, at 6.
\textsuperscript{42} See CAL. WELF. & INST. CODE § 396 (West 1997).
happy and healthy life,” the California legislature encourages families to seek other means of more stable care.\textsuperscript{43}

For mothers with HIV/AIDS, who often suffer mental as well as physical debilitation, foster care may be an unsolicited consequence of their disease. Mothers with HIV/AIDS may be subject to a DCS investigation or an individual petition questioning their ability to care for their children.\textsuperscript{44} On the other hand, mothers with HIV/AIDS may find the foster care system beneficial.\textsuperscript{45}

Related caregivers\textsuperscript{46} can receive either Aid to Families with Dependent Children (AFDC) or foster care benefits.\textsuperscript{47} A related caregiver may receive AFDC benefits if the child is deprived\textsuperscript{48} and the family is financially needy.\textsuperscript{49} AFDC recipients in California are automatically entitled to coverage of health care known as Medi-Cal.\textsuperscript{50} On the other hand, if the eligible foster care-giver opts for foster care benefits instead of AFDC, only the foster child automatically receives Medi-Cal and the entitlement is paid in advance of care.\textsuperscript{51} For an unrelated foster care-giver, the foster child is ineligible for AFDC.\textsuperscript{52} Foster care benefits, however, are more substantial than those of AFDC, often including back to school clothing allowances, increased rates for special needs children, and increased rates for older children.\textsuperscript{53} Therefore, a trusted friend or relative of a mother with HIV/AIDS may receive benefits that enable her or him to better care for the child if she or he becomes a foster parent.

Despite its benefits, foster care may only be viable in the short term, as the foster care system is designed to care for children only

\begin{itemize}
\item \textsuperscript{43} Id.
\item \textsuperscript{44} See LAFLA, supra note 36, at 5 (stating that “[t]ypically, DCS becomes alerted of a potential child abuse problem through its Hotline... from a police officer or from a school teacher. If, after investigation, it appears the child meets the requirements of § 300 [CAL. WELF. & INST. CODE § 300 (West 1997)], DCS will file a petition... The juvenile court will... decide whether the claims against the parent in the petition are true.”).
\item \textsuperscript{45} See LAFLA, supra note 36, at 12-19 (describing the benefits of Federal and State foster care benefit programs).
\item \textsuperscript{46} 45 C.F.R. § 233.90(c)(1)(v) (1995).
\item \textsuperscript{47} LAFLA, supra note 36, at 34.
\item \textsuperscript{48} 45 C.F.R. §§ 233.90, 233.100 (1995).
\item \textsuperscript{49} 45 C.F.R. § 233.20 (1995). Representative Maloney, who proposed the Standby Guardianship Act (“SGA”) as an amendment to the Social Security Act, also proposed the SGA as an amendment to the Adoption Promotion Act of 1997. This amendment would make federal funds for foster care and adoption assistance contingent on State passage of standby guardianship laws. See infra notes 66-68 and accompanying text.
\item \textsuperscript{50} LAFLA, supra note 36, at 34.
\item \textsuperscript{51} LAFLA, supra note 36, at 34.
\item \textsuperscript{52} LAFLA, supra note 36, at 34.
\item \textsuperscript{53} LAFLA, supra note 36, at 34.
\end{itemize}
temporarily. Case law verifies this inherent instability. The Supreme Court has ruled that, despite the assumption of the parental role by a foster care-giver, a foster family is not granted the same “liberty interest in family privacy” as is a “natural” family, particularly where the foster parent is unrelated. The strong emotional bond nurtured in a foster family stems from a “contract,” and thus is thought incapable of overriding any biological bond. Thus, controlling case law in the area of foster family rights establishes a formidable precedent against a mother with HIV/AIDS who hopes to place her child with a friend who has established rapport with the child and financial stability as a foster care-giver and seeks adoption or guardianship.

B. A Non-Legal Approach: The Dangers of Informal Guardianship Arrangements

By failing to exercise any of the legal options available, a mother with AIDS risks losing control over the long-term care of her children. Without a court-endorsed guardianship, her children may become wards of the State and placed with an unfamiliar caregiver or in an institution. A parent may be reluctant to turn to family members to help care for the children because of the societal stigma about HIV/AIDS, opting instead for less traditional choices for potential guardians, such as a sympathetic friend. With legal backing, an unrelated caregiver can receive foster care benefits. The same friend


55. Smith, 431 U.S. at 844.

56. Id. at 845.

57. For an illustration of this line of cases, see Drummond v. Fulton County Dep’t of Family & Children’s Serv., 563 F.2d 1200 (5th Cir. 1977) (en banc) (ruling that a foster family did not have liberty interest “of full-fledged constitutional magnitude” to contest minimal but adequate state procedures for removal of foster children); Kyees v. County Dep’t of Pub. Welfare, 600 F.2d 693 (7th Cir. 1979) (removing foster children from foster family without any hearings/procedure not a deprivation of a liberty interest on the part of foster parents); Sherrard v. Owens, 484 F. Supp. 728 (W.D. Mich. 1980) (noting that foster parents have no family liberty interest and therefore are not entitled to due process requirements).

58. See infra notes 235-51 and accompanying text; see also Symposium, supra note 34.

59. The California Department of Social Services publishes its regulations in the Manual of Policies and Procedures (MPP). Related caregivers are governed by the MPP. A child who lives in the home of a “caretaker relative” is eligible for AFDC. MPP §§ 80-301 (c)(1); 82-808.1, 82-808.2 (1994) ; CAL. WELF. INST. CODE § 11203 (1994). A “caretaker relative” is limited to a parent, stepparent, sibling/step-sibling/half-sibling, grandparent, great-grandparent, aunt, uncle, cousin/first cousin, niece or nephew. MPP § 82-880.111 (1994). Related caregivers must meet income requirements for eligibility. For unrelated caregivers, no government benefits on
cannot, however, receive any government benefits without court endorsement of the arrangement. Even if the informal, unrelated caregiver opens his or her home to the children, the children are not entitled to the mother’s government benefits or county funding for family maintenance.

A recent Illinois case underscores the importance of using the legal options available to prepare for the future care of the child. Petitioner-mother, diagnosed with AIDS, had filed a guardianship petition appointing her sister as guardian. This petition was denied without testimony or argument by the trial court, which found that the court needed more time to investigate the sister’s suitability as guardian, that no guardian was needed while petitioner could still care for her children, and that when petitioner became unable to care for her children, she could then file for emergency temporary guardianship. The appellate court reversed this decision and granted the standby guardianship the mother had fashioned. The court cited Illinois’ pending Standby Guardianship Law, Public Act 88-202, which would take effect three months after the proceeding, as a strong reason to support the mother’s petition. By recognizing upcoming legislation and the policies underlying it, the Illinois court enabled one mother to realize her future plans for her children. In re Estate of Herrod illustrates the potential for compassion and reasonableness of courts encountering cases in which the mother attempts to exercise legal options.

C. A New Alternative for Mothers with HIV/AIDS: The Federal Standby Guardianship Act

1. The Proposed Statute

SEC. 478. STANDBY GUARDIANSHIP LAWS AND PROCEDURES. A proposed federal statute would provide states with incentives to pass a standby guardianship law. To be eligible for payments under 42 U.S.C. §§ 670-679, a state must have in effect laws and procedures that permit any parent who is chronically ill or near

60. MPP § 82-880.2, 3 (1994).
62. Id.
63. Id. at 1063.
64. Id. at 1065.
65. Id.
death, without surrendering parental rights, to designate a standby guardian for the parent's minor children, whose authority would take effect upon:

(1) the death of the parent;
(2) the mental incapacity of the parent; or
(3) the physical debilitation and consent of the parent.66

This proposed amendment is estimated to have a zero-to-one-percent chance of passing in Congress.67 Despite almost identical language to the flagship New York statute, which has proven to be successful, the federal version seems destined to lie dormant for years to come.68

2. A Comparison of Existing State Statutes: California's Joint Guardianship and Standby Guardianship Laws


Enacted in 1994, California's Joint Guardianship Law ("JGL") addresses the concerns of terminally ill parents, enabling them to plan for their children's future.69 The new law remedies the problem of terminally ill parents relinquishing their parental rights in order to provide care for their children after their death.70 California's law removes uncertainty by allowing a mother with AIDS (or any parent with a terminal illness)71 to initiate the joint guardianship proceed-

66. H.R. 709, 104th Cong. (1995), available in LEXIS/NEXIS, LEGIS Library, BLTRCK 104 File. Representative Maloney (D-NY), the original sponsor of this proposal, attempted to bring the issue to the forefront again. On April 30, 1997, Ms. Maloney proposed an amendment to 105 H.R. 867, the Adoption Promotion Act of 1997, which has passed the House and is pending in the Senate. Her amendment, section 202 of the Act, won by voice vote in the House. The section 202 amendment makes federal funds for foster care and adoption assistance contingent on State legislation of standby guardianship laws. Otherwise, the language of this amendment mirrors the language quoted here. However, its chances of enactment are equally in limbo. Library of Congress Report on the Internet, supra note 7.


68. For more information about the New York Standby Guardianship Law, see infra Part I.C.2.b.

69. See CAL. PROB. CODE §§ 2105, 2250, 3611 (amended) (West 1997) (explaining joint guardians or conservators and appointment, petition for appointment, and order of court, respectively); see also CAL. PROB. CODE § 1419.5 (added) (West Supp. 1994) (defining custodial parents).

70. Symposium, supra note 34, at 159.

71. The text of the Joint Guardianship statute reads "a custodial parent diagnosed as having a terminal condition" and does not specify any type or types of conditions. The statute defines "terminal condition" as "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, within reasonable medical judgment, result in death (within two years)." CAL. PROB. CODE § 2105(f) (West Supp. 1994).
ings at a point where she can still witness the outcome. Joint guardianship does not require the mother to relinquish parental rights; instead she shares them with her designated guardian. The new law enables parents with terminal illnesses to plan for the future care of their children. The JGL states in part:

If a custodial parent has been diagnosed as having a terminal condition, as evidenced in a declaration executed by a licensed physician, the court, in its discretion, may appoint the custodial parent and a person nominated by the custodial parent as joint guardians of the person of the minor. However, this appointment shall not be made over the objection of a noncustodial parent without a finding that the noncustodial parent's custody would be detrimental to the minor, as provided in Section 3041 of the Family Code.

The JGL enables parents to retain custodial rights until they can no longer care for their children, after which time the designated guardian, already approved by the court, gains custody. Advantages of using the JGL include the opportunity for the parent to advocate her choice of guardian before the court, especially if that choice is "unorthodox"; the assurance that the designated guardian will be the legal caregiver; and the chance for the mother, child, and future guardian to establish a strong relationship together. In essence, California's Joint Guardianship Law, by legally endorsing a parent's choice of guardianship prior to the parent's death or incapacitation, reduces uncertainty about his or her child's future.

b. Standby Guardianship Laws: Another Potential Legal Option for Women with HIV/AIDS

Other states have enacted their own versions of standby guardian-
The policies underlying such laws assist the ever-growing population of parents with HIV/AIDS and other terminal illnesses with their efforts to plan for their children's futures. Such laws permit the appointment of non-parental guardians by the parent/guardian prior to the parent's death, so that non-parent appointees assume guardianship upon death or incapacitation of the parent.

Standby guardianships, however, operate differently from joint guardianships. Under a standby guardianship, the appointed guardian does not assume guardianship until a "triggering event" occurs. The death, incapacitation, debilitation, or consent of the parent can trigger the transfer of legal guardianship over minor children. Some state statutes expressly define the triggering events of incapacitation and debilitation, while others are less clear. For instance, Maryland, New Jersey, and Illinois require a physician's letter to substantiate the parent's incapacity or debilitation.

The statutes addressing guardianship differ on the timing of the


81. Symposium, supra note 34, at 159 (discussing guardianship problems and possible solutions women with HIV face); Alice Herb, The New York State Standby Guardianship Law: A New Option for Terminally Ill Parents, in ORPHANS, supra note 3, at 88.

82. Symposium, supra note 34, at 159.

83. See CAL. PROB. CODE § 2105(f) (West Supp. 1994); see also N.Y. PUB. HEALTH LAW §§ 290-1726 (McKinney 1992); N.Y. SURR. CT. PROC. ACT LAW Art. 17, § 1726 (McKinney 1997).


86. See, e.g., CONN. GEN. STAT. § 45a-624 (1995) (listing death as a trigger of guardianship).

87. Id. (listing incapacitation as a trigger of guardianship).

88. Id. (listing debilitation as a trigger of guardianship).


90. See Pinott, supra note 14, at 81 (describing the various kinds of events that trigger transfer of legal guardianship).

91. See, e.g., ILL. REV. STAT. ch. 755.5 (1995) (describing incapacitation as the "inability to make and carry out day to day child care decisions"); CONN. GEN. STAT. § 45a-624 (1995) (listing several categories for incapacitation and debilitation followed by disclaimer that these conditions are "not limited to" listed categories); N.C. BILL 682 (1995) (defining both incapacitation and debilitation as being "chronic and substantial inability to care for child"); WIS. STAT. § 880.36 (1995) (defining incapacitation and debilitation as "incapable of exercising legal guardianship").

transfer of guardianship rights. Standby guardianships commence upon the death or incapacitation of the parent with HIV/AIDS.\textsuperscript{93} Conversely, joint guardianship is automatically assumed when the court approves the nominee, an assumption which carries with it some potentially negative aspects for parents establishing guardianships.\textsuperscript{94} Under a Joint Guardianship statute, the parent and designated guardian share authority over a child’s day-to-day activities.\textsuperscript{95} The parent and appointed guardian must agree to the medical, educational, and living arrangements for the child.\textsuperscript{96} When parent and guardian do not agree, however, the law provides little guidance;\textsuperscript{97} there is no legal presumption that the biological parent prevails.\textsuperscript{98} Additionally, joint guardianship allows the designated guardian to petition for a court order allowing her to act independently where the parent, incapacitated or debilitated, has failed to act.\textsuperscript{99} Conversely, in standby guardianship jurisdictions, the parent does not share guardianship of her child until the court confirms one of the triggering events.\textsuperscript{100} Thus, under a standby guardianship provision a parent maintains greater authority over the child’s daily life, even after court approval of her designated guardian.\textsuperscript{101}

Standby guardianships are activated when a triggering event occurs, and thus differ from a joint guardianship, where the nominee, upon appointment, assumes guardianship.\textsuperscript{102} In some states, the parent retains the power to revoke a standby guardian prior to appointment, subject to court approval.\textsuperscript{103} Revocation requires filing a writ-

\begin{itemize}
\item \textsuperscript{93} Symposium, supra note 34, at 158-61.
\item \textsuperscript{94} Symposium, supra note 34, at 159.
\item \textsuperscript{95} See, e.g., CAL. PROB. CODE § 2105(c)(1) (West Supp. 1994) (explaining “[w]here there are two guardians or conservators, both must concur to exercise a power”).
\item \textsuperscript{96} See Symposium, supra note 34, at 160 (discussing how joint guardianships may be disadvantageous because guardians must agree in exercising their power. Further, there is no legal guidance with regard to resolving disputes between guardians).
\item \textsuperscript{97} See id.
\item \textsuperscript{98} See id.
\item \textsuperscript{99} See, e.g., CAL. PROB. CODE § 2105(e) (West Supp. 1994) (stating “[w]here joint guardians or conservators have been appointed and one or more are (1) absent from the state and unable to act, (2) otherwise unable to act, or (3) legally disqualified from serving, the court may, by order made with or without notice, authorize the remaining joint guardians or conservators to act as to all matters embraced within its order”).
\item \textsuperscript{100} See N.Y. PUB. HEALTH LAW § 290-1726 (McKinney 1992); see also N.Y. SURR. CT. PROC. ACT LAW Art. 17, § 1726 (McKinney 1997).
\item \textsuperscript{101} See N.Y. PUB. HEALTH LAW § 290-1726 (McKinney 1992).
\item \textsuperscript{102} Id.
\item \textsuperscript{103} Connecticut, Florida, Maryland, North Carolina, New Jersey, New York and Pennsylvania all allow parental revocation in their Standby Guardianship statutes. See CONN. GEN. STAT. § 45a-624f (1997) (allowing “[t]he principal [to] revoke a designation of a standby guardian at any time by written revocation and notification of the revocation to the standby guardian.”); see
\end{itemize}
ten petition with the court.\textsuperscript{104} Statutes also prescribe time frames from twenty to 180 days for appointed standby guardians to file confirmation petitions of their guardianship with the court.\textsuperscript{105} Additionally, some statutes permit appointment of multiple standby guardians or alternate standby guardians subject to the same requirements.\textsuperscript{106}

Since a standby guardian only assumes guardianship after a triggering event occurs, verification of the triggering event is critical. In most states, laws include safeguards to assure that the parent will remain sole guardian for as long as she is able.\textsuperscript{107} Two examples of such safeguards include an explicit definition of the triggering events and a requirement that a physician verify the triggering event.\textsuperscript{108} Some definitions, however, are broad or vague; for example, showing that the parent is "incapable of exercising legal guardianship" or "displays 'chronic and substantial inability'" to care for the child.\textsuperscript{109} Additionally, some states do not require medical documentation.\textsuperscript{110} While less stringent standards may simplify the process for mothers with HIV/AIDS at a time when they may not have access to attorneys or doctors,\textsuperscript{111} they do not protect mothers when designees want to as-

\footnotesize
\begin{itemize}
\item \textsuperscript{104} New Jersey, North Carolina, and Pennsylvania do not always require the filing of a written revocation. \textit{See infra} note 105.
\item \textsuperscript{105} Florida requires the standby guardian to petition for confirmation within 20 days. \textit{See} FLA. STAT. ch. 744.304 (1995). Other states have different time requirements. \textit{See}, e.g., CONN. GEN. STAT. \textsuperscript{(b)(1)(2)(3)} (1995); N.J. STAT. ANN. \textsuperscript{§} 3B:12-75e (West 1997) (stating "[a] designator may revoke a designation of standby guardianship by notifying the designated standby guardian orally or in writing or by any other act evidencing a specific intent to revoke the designation"); NY. FAM. CT. ACT \textsuperscript{§} 661 (McKinney 1997); N.C. GEN. STAT. \textsuperscript{§} 35A-1370 (1995); 20 PA. CONS. STAT. ANN. \textsuperscript{§} 5113 (West 1995).
\item \textsuperscript{107} Florida, Maryland, New York, and Pennsylvania do not always require medical documentation. \textit{See infra} note 105.
\item \textsuperscript{108} Florida, Maryland, New York, and Pennsylvania permit alternate standby guardians. Illinois provides for a short term guardian to be appointed by the parent without court approval for a 60-day period. \textit{See supra} notes 80 and 83.
\item \textsuperscript{109} Connecticut, Florida, New York, and Wisconsin do not require medical documentation. \textit{See supra} note 103 (stating statutes with this requirement).
\item \textsuperscript{111} Symposium, \textit{supra} note 34, at 156. Still, most states have yet to enact Joint or Standby Guardianship laws. Perhaps the AIDS epidemic has not yet hit these areas with a force comparable to that with which it has hit the states that have these laws. \textit{See} NIAID Report, \textit{supra} note 1 (explaining that AIDS is the number one cause of death in fifteen major American cities). Seen as a logical extension of proposed federal Standby Guardianship Acts pertaining to mentally
sume guardianship sooner than the mother would like.\textsuperscript{112}

Despite such drawbacks, practitioners implementing guardianships under joint and standby guardianship laws recognize the value of these alternative laws for women with HIV/AIDS.\textsuperscript{113} As Marina T. Sarmiento, Outreach Director of San Francisco's AIDS Legal Referral Panel, states, ""[d]espite these potential problems and ambiguities, [joint or standby] guardianships can make a significant difference in the life of a mother with AIDS and in the lives of her children."\textsuperscript{114}

c. The Practical Advantages of Enacting Joint/Standby Guardianship Laws

Although women with HIV/AIDS tend to seek legal assistance less often than men with HIV/AIDS, as the number of women with HIV increases, the demand for legal services for AIDS-affected families will also increase.\textsuperscript{115} For women without access to legal services, the legal options of wills, custody proceedings, and guardianships are not realistic alternatives.\textsuperscript{116} Additionally, convincing the mother that exercising her legal options is in her and her children's best interests may be more difficult where the laws do not accommodate her family's needs.\textsuperscript{117} In states without joint or standby guardianship laws, attorneys and mothers with HIV/AIDS must use existing law to accomplish an outcome that fits the mother's needs.\textsuperscript{118} As a New York attorney working with mothers with HIV/AIDS reveals: "Nothing can take away the pain of planning for another person to raise one's children. But the [standby guardianship] law . . . can help make the pro-

\textsuperscript{112} See Symposium, supra note 34, at 156 (discussing problems encountered by HIV-positive women seeking and using legal services).

\textsuperscript{113} See, e.g., Symposium, supra note 34, at 158-61 (discussing the practical advantages of Joint and Standby Guardianship laws for women with HIV/AIDS).

\textsuperscript{114} Symposium, supra note 34, at 161.

\textsuperscript{115} Symposium, supra note 34, at 156 (noting the increasing impact of HIV/AIDS on family law issues).

\textsuperscript{116} See infra Part I (discussing current law and the legal options available to mothers with HIV/AIDS).

\textsuperscript{117} See Symposium, supra note 34, at 159 (explaining that women historically do not choose to petition for guardianship because they lose parental authority over their children and are therefore forced to choose between maintaining parental authority or planning for their children's future).

\textsuperscript{118} See supra notes 11-13 and accompanying text.
cess more compassionate... parents can go forward, leading their lives and loving their children, knowing their future is assured."

III. THE PROPOSED FEDERAL STANDBY GUARDIANSHIP ACT ENHANCES POSITIVE OUTCOMES FOR THE CHILD

"One of the most difficult and painful realizations for a mother is the possibility that she will not have the opportunity to care for her children and help them grow into maturity." Mothers with AIDS often see this as the worst consequence of the disease. Service providers have an obligation to encourage a mother with AIDS to plan for the future care of her children and inform her of all of her legal options.

A. How the Proposed Federal Standby Guardianship Act Facilitates a Smooth Outcome for Children Orphaned By AIDS

The proposed Federal Standby Guardianship Act enhances the opportunity for the child to adjust to his or her new caregiver by permitting court approval of the designated guardian prior to the parent’s death. More time is available for building a relationship between the guardian and the child with the mother’s help, resulting in a smoother transition. If the mother is medically and emotionally able, spending time with her child and the guardian lets the child know that his or her mother supports the future arrangement, and that developing a strong relationship with the guardian will not damage the mother-child bond. If the mother is not able to do this, she can request that another trusted adult help the child adjust to his or her new caregiver.

1. The Proposed Federal Standby Guardianship Act Provides "Shared Time"

By spending time with the child before assuming guardianship, the future caregiver can better prepare for the child’s smooth transition. The future caregiver can learn the child’s daily schedule and habits,

119. Pinott, supra note 14, at 81.
120. Pinott, supra note 14, at 75.
121. Pinott, supra note 14, at 75.
123. See Pinott, supra note 14, at 80-81 (explaining the advantages of the SGA for children of HIV-infected parents).
124. Symposium, supra note 34, at 159; Herb, supra note 81, at 87.
as well as introduce the child to the child’s new home.\textsuperscript{125}

Examples of how the proposed Standby Guardianship Act allows children to adjust smoothly to a new home reveal the importance of this law to HIV/AIDS-affected families and the service providers who support them. In a California case that utilized the JGL, a terminally ill mother secured her children’s aunt and uncle as joint guardians, thereby precluding the children’s father, who had sexually abused them, from gaining custody.\textsuperscript{126} In another case, a pregnant mother with AIDS convinced a court to appoint herself and a close friend joint guardians of the unborn baby.\textsuperscript{127}

2. The Proposed Federal Standby Guardianship Act Accommodates the Need to Keep Siblings Together

Children who experience the death of a parent from AIDS undergo great instability and emotional and physical upheaval.\textsuperscript{128} In a progressive New York case petitioned under that state’s Standby Guardianship Law, a court recognized the importance of keeping siblings together and appointed the mother’s 18-year-old daughter the standby guardian of her six-year-old brother because no other “adult resources” were available.\textsuperscript{129} If a less sympathetic court, however, determines the future care of children whose parent(s) have died of HIV/AIDS, these children may be “torn from their last psychological bond, a brother or sister, during the height of their greatest emotional plight.”\textsuperscript{130} For example, California places the most siblings in out-of-home care, and its juvenile court is not obligated by law to make any effort towards placing siblings in the same home.\textsuperscript{131} In the absence of any statutory duty, a parent cannot ensure that her children will remain together unless she can designate a guardian, approved by the court, who is willing to care for all of her children. Al-

\textsuperscript{125} See Symposium, supra note 34, at 160 (explaining the advantages of naming a guardian prior to a natural parent’s death).

\textsuperscript{126} Both this case description and the case description which immediately follows are excerpted from the case files of Public Counsel’s Children’s Rights Project. In the case where the child’s father was not allowed to gain custody of his children, he first was shown to be “unfit”; the appointed guardians were then shown to be the best caretakers in a “best interests of the child” analysis. See supra note 31; infra Part II.B.2.b.

\textsuperscript{127} See supra note 31; infra Part II.B.2.b.

\textsuperscript{128} See ORPHANS, supra note 3, at xiii (describing the unique circumstances surrounding the death of a parent from AIDS).

\textsuperscript{129} Pinott, supra note 14, at 83.

\textsuperscript{130} William Wesley Patton & Sara Latz, Severing Hansel from Gretel: An Analysis of Siblings’ Association Rights, 48 U. MIAMI L. REV. 745, 746 (1994) (advocating that siblings be provided protection, and an affirmative legal duty to keep siblings together).

\textsuperscript{131} See id. (describing the tenuous legal protections afforded to sibling relationships).
though courts recognize that parents have a fundamental right to raise their children, they have not determined that siblings have a right to associate. The proposed Federal Standby Guardianship Act contains the added assurance that the siblings will be able to stay together with a caregiver who is chosen by the mother and familiar to the family.

B. The Role of the Attorney: Addressing the Legal and Social Needs of Stakeholders In Joint Guardianship Proceedings

While the proposed Federal Standby Guardianship Act provides for the legal needs of HIV/AIDS affected families, it also considers the social needs of these families. By allowing for more planning time and preparation, the Federal Standby Guardianship Act could become an important tool in ensuring a smooth transition for the children of HIV/AIDS-affected families. In order to accomplish this goal, legal advocates for these families must be sensitive and able to cope with the stress of each family member. Attorneys must work with service providers, social workers, and case managers to ensure that the children, parents, and potential guardians (both related and unrelated) are connected to necessary support services.

1. The Children

Legal advocates who work with this population must remember that while losing a parent is never easy, watching a parent die of HIV/AIDS is an especially harrowing experience. Attorneys are obligated to inform each family member of his or her legal options in a way each member, including children, can understand. Under the proposed Federal Standby Guardianship Act, the attorney could enlist the parent's expertise in explaining the legal process of guardianship to the child. Unless a cure is found, or until the spread of AIDS decreases, the number of children orphaned by AIDS in the United States is conservatively projected to reach over 80,000 by the year


133. Patton & Latz, supra note 130, at 768.

134. See ORPHANS, supra note 3, at xiii (explaining the need for social services' support of HIV-affected families).

135. See ORPHANS, supra note 3, at xiii (describing the unique emotional costs to children whose parents die of AIDS and stating, "[C]hildren whose parents die of HIV/AIDS undergo a particularly wounding experience that encompasses stigma, secrecy, and denial, as they witness their parents' physical and often mental deterioration.")
One common characteristic between these children is having to cope with a parent's death. To address the varied legal and social needs of these children, support services must be individualized and child-centered. Focusing on the child's "age, prior psychological state, cultural background, and HIV status" will make intervention efforts more responsive. In addition, acknowledgement of the strengths these children have cultivated as a result of their experiences is important in understanding and facilitating their needs. In considering multi-children families, it is important to recognize and retain the support system between siblings; thus, keeping siblings together when possible becomes another goal in future childcare planning.

a. The Age of the Child

The attorney working with a child orphaned by AIDS needs to provide that child with important information regarding his or her parent's legal alternatives and choices and how those choices will affect the child. To do this effectively, the attorney must determine how the child will best understand this information. Each child understands illness and death differently depending on age. For example, a very young child may not understand that when an ill parent refuses to do things with the child, it is because of inability, not indifference. An adolescent may be more attuned to the social stigma attached to AIDS, and the resulting sense of shame may lead that child to bury his or her feelings of loss. Understanding their loss and sorting out these feelings is essential for all children orphaned by AIDS, but the process must be sensitive to age-related capacities to

136. The range has been estimated at 72,000 to 125,000 children. See ORPHANS, supra note 3, at 6.
137. See Retkin, Stein, & Draimin, supra note 122, at 539-40 (describing the appropriate approach for legal and social service providers working with families with HIV/AIDS parents).
139. See Patton & Latz, supra note 130, at 764-65 (discussing the importance of sibling bonds to individual and family functioning and how the attachment in the sibling relationship consequently determines a child's future psychopathology and development).
140. See Retkin, Stein, & Draimin, supra note 122, at 546-47 (explaining the lawyer's obligations to his or her client in HIV/AIDS-related issues).
141. See Dudley, supra note 138, at 56 (noting age-specific responses to having a parent with HIV/AIDS).
142. Dudley, supra note 138, at 56.
143. See Barbara Draimin, Adolescents in Families with AIDS: Growing Up with Loss, in ORPHANS, supra note 3 (describing adolescents' perceptions of parents with HIV/AIDS).
144. See id. at 19-21 (describing the coping mechanisms of adolescents with parents with HIV/AIDS).
understand.

i) Very Young Children

Toddlers and primary school age children may not fully comprehend what is happening to their parent with AIDS, although they are very sensitive to what occurs around them. For this age group, "death means a separation which can be felt as overwhelming abandonment, rejection and panic."145 Many children of this age make irrational associations, such as linking what the parent wore when she died to the cause of death.146 This type of thinking can often occur when adults avoid or euphemize discussion about the parent's death in the children's presence.147

One mother who attempted to keep AIDS-related conversations out of earshot of her two and one-half year-old toddler realized that her child noticed that his parents abruptly left the room to discuss treatments.148 His mother "suddenly understood that we had been treating him like a shadow in our midst."149 As a result, she began to tell Zach, her son, about her husband's disease.

In response, Zach began emulating his father. Zach stated that he, too, wanted a "big cough" when he grew up and claimed he could not walk unsupported, so he could not leave the house for nursery school.150 When Zach contracted a cold, he insisted on using the same cough drops as his father.151 The word "virus," which his mother chose to use to describe his father's condition, triggered fearful responses in Zach, because he heard it frequently on television, from his pediatrician to describe a minor illness, and from family friends discussing the winter flu.152

Zach was four years old when his father died.153 His first reactions included claiming his father's things, questioning where a body goes...
after life, and dreaming about playing with his father again. The grieving and learning process has not stopped; Zach’s mother states that “having the door open for him to ask and learn has helped him grow.” This underscores the need to be accessible to and honest with children of all ages.

**ii) Older Children and Adolescents**

Older children tend to have a more sophisticated understanding of death. This understanding, coupled with the greater autonomy of an older child, may give rise to concerns about finances, housework, and care of younger siblings after the death of an HIV-infected parent. Adding to these practical worries, many adolescents in this group have also experienced other recent, personal losses, such as divorce, death or incarceration of a family member or significant other. Without a strong social support network, an adolescent may feel overwhelmed by all of these pressures, pressures which may manifest in negative behaviors, such as “acting out” at home and school, doing poorly academically, and experiencing friction with law enforcement. To cope with the death of a parent, some young people withdraw or opt to mourn privately, shunning public memorials.

To help an older child or adolescent deal with this emotionally exhausting situation, a supportive adult should ask the child about the child’s feelings regarding death and mourning. Having someone who can honestly and openly discuss the death of a parent is crucial to a child of any age who confronts innumerable questions, yet feels isolated and uncertain. An adult, such as an attorney, entrusted with the task of explaining the guardianship process may also help answer an older child’s practical concerns. To address these questions successfully, the adult must be sensitive to the child’s ability to discuss these matters. The proposed Federal Standby Guardianship

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156. See Dane, *supra* note 146, at 62 (noting that older children who lose a parent to AIDS feel “compelled ... to act in a more adult fashion”).
161. Dane, *supra* note 146, at 68.
162. Dane, *supra* note 146, at 68.
Act enables this discussion to include the parent, whose knowledge and support of the child will facilitate future planning with the child's wishes in mind.  

b. Psychological Background of the Child

An attorney who works with AIDS-affected families must be sensitive to the psychological toll of the parent(s') death and possible additional family problems, including poverty, stigma from HIV/AIDS, or substance abuse, on the child. As previously mentioned, many children and adolescents who lose a parent to AIDS have had other family troubles, such as divorce, death and/or incarceration of family members. Many of these children show signs of depression, anxiety and other psychological problems that need attention as much as coping with the parent's death.

Often overlooked, however, is the strength these children have developed in coping with HIV or surviving other family problems. Support service providers should consider these strengths as the building blocks for each child's intervention plan. School personnel may first alert service providers to problems. The stressful conditions that these children experience may lead to inappropriate conduct at home and school, creating a higher incidence of at-risk behavior among AIDS orphans than among the "average" children. An attorney plays a special role in helping the family determine when and how to disclose its HIV-affected status; the attorney and family should discuss legal ramifications and remedies. This Article addresses the issue of disclosure to schools and service providers in the next section, discussing parents as stakeholders.

165. See supra note 8.
166. See supra note 138, at 56.
167. Dane, supra note 146, at 56.
168. Dane, supra note 146, at 56.
169. Dane, supra note 146, at 56.
170. Dudley, supra note 138, at 56.
171. Dudley, supra note 138, at 56.
172. Dudley, supra note 138, at 56.
173. For example, upon disclosure, it is likely the family will feel isolated from friends and community, particularly if the reaction to disclosure displays fear or stigma. Discrimination on the basis of AIDS, however, is a recognized cause of action under the Americans with Disabilities Act, 42 U.S.C. § 12101 (1990). David L. Schulman, Supervising Attorney for the Los Angeles City Attorney's Office AIDS Discrimination Unit, the first city attorney appointed to a unit of this kind in the United States, has written extensively on AIDS discrimination. See, e.g., David L. Schulman, AIDS Workplace Law and Policy: A Systematic Analysis, 9 ST. LOUIS U. PUB. L. REV. 543 (1990).
c. Cultural Background of the Child and the Child's Family

The National Institute of Allergy and Infectious Diseases reported that out of 58,000 known cases of adult and teen women infected with AIDS, a majority of these women are African American or Latina.\(^{174}\) Families of different cultures may deal with death differently.\(^{175}\) Dealing with death by AIDS may be especially difficult due to the extreme physical suffering of the afflicted and the social stigma some associate with the disease.\(^{176}\) An attorney who is helping the family plan for the child's future care needs to recognize that a child's culture is an important aspect of providing appropriate support services.\(^{177}\)

For example, it is important to understand the individual family's definition of the term "family."\(^{178}\) In many cultures, "family" includes non-biologically related persons.\(^{179}\) A service provider may overlook the best prospective guardian for the child if she or he does not include extended family members.\(^{180}\) Cultural background and beliefs may also affect disclosure of a family member's HIV status. For in-

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174. NIAID Report, supra note 1, at 1. Almost half of all people infected with HIV/AIDS in the United States are people of color. AIDS is the leading cause of death for Americans in the age range of 25-44. Facts About AIDS, supra note 1, at 6.
175. Dudley, supra note 138, at 57.
176. ORPHANS, supra note 3, at xiii.
177. Dudley, supra note 138, at 57.
178. The changing composition of the modern family has been thoroughly examined in a variety of contexts in the legal literature. See, e.g., Dorothy E. Roberts, The Genetic Tie, 62 U. CHI. L. REV. 209 (1995) ("[H]owever important the biological bond is as a basis for family relationships, it need not be the exclusive bond. In fact, blood ties are less significant to the definition of family in the Black community than they have traditionally been for white America."); Ruth Ben-Israel, Social Security in the Year 2000: Potentialities and Problems, 16 COMP. LAB. L. J. 139, 159 (1995) ("The changing family structure first will require the adaptation of social security schemes that better reflect the current structure of society. The definition of family thus will need to be extended to provide new patterns of family. . . ."); Elizabeth Bartholet, Defining Family: Adoption Law & Policy, 2 DUKE J. GENDER L. & POL'y 5, 6 (1993) ("Typically, we think of family as meaning a man and a woman raising their bio-product child. But both traditional adoption and non-traditional reproductive techniques make it clear that this definition of family is a matter of choice—it is not determined by nature."); Note, Patriarchy is Such a Drag: The Strategic Possibilities of a Postmodern Account of Gender, 108 HARV. L. REV. 1973 (1995):

Legal definitions of family have traditionally relied on a formalist approach, which presumes the word 'family' refers to relationships based on blood, marriage or adoption and therefore excludes non-traditional arrangements. The functionalist approach, of more recent vintage than formalism, recognizes as familial those relationships that serve the same purposes as the traditional family, namely to provide economic support and a loving environment in which to raise children.

Id.

179. Dudley, supra note 138, at 57. "Though courts often stress that biological relationships are central to the definition of family, the Supreme Court has stated clearly that 'biological relationships are not exclusive determinants of the existence of a family.'" Geballe, supra note 4, at 145.
stance, a traditional Chinese-American family, following the Confucian proverb “eat your own bitterness,” may not want to share family problems with anyone outside the family. Euphemisms referring to death may also be used with children. Common Spanish expressions for death are “se falleció” (he failed) or “él está con Dios” (he is with God). An expression for death used by many African-American families is “passing.” One woman remembers hearing her father had “passed” when she was five years old; two years later she understood that she would never see her father again. It is important for the service provider to appreciate the child’s ability to understand the family’s way of explaining death, for the child may not fully comprehend the meanings of such euphemisms.

d. HIV Status of the Child

The struggle inherent in helping a child cope with the death of a parent from AIDS is compounded when the child is infected with the same disease. An attorney can assist children who face obstacles to schools and other support services. The most obvious example of a child with HIV/AIDS is an infant whose mother transmitted the disease during pregnancy. Increasing numbers of adolescents, however, contract AIDS through unprotected sex, drug use, and sexual abuse. Some of these adolescents have parents with AIDS; for those who have experienced an AIDS-related death in their families, many report the death made them reevaluate their own risky behaviors. Others rebelled against the death by denying the risk of their own activities, and still others saw their own lives as hopeless and believed it was too late to benefit from any changed behavior.

183. Id.
184. Id.
185. Dudley, supra note 138, at 56.
188. Dudley, supra note 138, at 59.
189. Dudley, supra note 138, at 59. The Centers for Disease Control and Prevention found that in the United States, the majority of people with HIV/AIDS are in their twenties and thirties; many contracted the disease while in their teens. AIDS is the leading cause of death for Americans in the age range of 25-44. Facts About AIDS, supra note 1. Another reason children with HIV/AIDS feel hopeless may be the lack of medicinal options available to them. Minors are generally barred from participation in commercial drug tests, and cautious FDA regulations do not consider these drugs’ effects on children. The expense of treatments for HIV/AIDS, see supra note 5, coupled with the uncertain effects on children, make doctors’ treatment reluctant and risky. Susan Brink, Not for Adults Only: Doctors and Parents Try the Unproven to Save Sick Kids, U.S. NEWS & WORLD REPORT, Sept. 29, 1997, at 70.
Innovative programs such as New York’s Informed Schools Project (“Project”) recognize the unique needs of HIV-positive children. The Project begins with support services for parents to help them decide if and when they will disclose their children’s status to the school. A child advocate then meets with the school’s principal to ensure that the school staff completed AIDS training and report the results to the parent. Next, if the parent wishes to disclose, she or he meets with the principal, teacher, and child advocate to discuss the needs of the child. The child advocate’s main function is to ensure the privacy of the parent and child. The response of school personnel has been positive and effective during the initial stages of this project. Hopefully, with heightened awareness and understanding of AIDS, support services projects like this will continue to develop and serve children with HIV.

e. Reprise: The Role of the Service Providers

Attorneys and other service providers helping these children must be aware of the personal fears and confusion stemming from AIDS that these children confront, as well as the grieving process involved with the death of their parents. The great diversity of the children orphaned by AIDS, which is not limited to the five factors discussed above, necessitates broad-based, flexible intervention strategies truly designed to meet the specific needs of these children. Without this flexibility, service providers cannot hope to adequately provide services for AIDS orphans.

2. The Parents

In the majority of the cases discussed in this Article, the HIV/AIDS-affected family consists of a single parent with AIDS, who is the custodial parent; the non-custodial parent is either absent or has already

191. Id. at 98.
192. Salerno, Leonard, & Hittelman, supra note 190, at 98.
193. Salerno, Leonard, & Hittelman, supra note 190, at 98.
194. Salerno, Leonard, & Hittelman, supra note 190, at 98.
197. Dane, supra note 146, at 67-68.
199. See supra notes 1-3 and accompanying text.
The custodial parent with AIDS must not only deal with her own needs and fears, but must also plan for her children’s future. The proposed Federal Standby Guardianship Act will ensure such a parent that her choice of a future guardian is respected. She still, however, must help prepare herself, her children, and the prospective guardian for the process. Perhaps equally challenging to her are issues of disclosure. To effectively face these challenges, she will need access to support services.

The non-custodial parent may cause conflict in the standby guardianship proceeding. He must be notified of the proceedings and may choose either to consent or to contest the guardianship. Because courts generally follow a policy of preserving the family unit, the role of the non-custodial parent must not be forgotten.

a. The Custodial Parent With HIV

An HIV-infected parent may feel she has no control over her emotions:

When I found out I was HIV positive, all I could think about was dying. And when I thought about dying, all I could think about was Matt, my nine-year-old son. I worried about what would happen to him when I died. I was so despondent that I even stood one day for hours by a window, thinking about taking my own life. But I could not do that, not to Matt.

The parent must not only cope with her disease, but may also want to explain it to her children so they can begin to plan for their future without her. In this situation, she requires support services to help

200. See supra notes 1-3 and accompanying text.
201. Susan L. Waysdorf, Families in the AIDS Crisis: Access, Equality, Empowerment, and the Role of Kinship Caregivers, 3 TEX. J. WOMEN & L. 145, 214-15 (indicating that the proposed legislation will allow parents with AIDS to “participat[e] in and control decisions concerning the guardianship of their children”).
203. Herb, supra note 81, at 90 (commenting that “the other biological parent retains his right to petition the court at any time for custody of his children”).
204. Pinott, supra note 14, at 78.
205. See, e.g., CAL. PROB. CODE § 2105(f) (West 1995); FLA. STAT. ch. 744.304(1) (1981).
206. The courts and legislatures have placed a strong emphasis on including both parents in any proceedings regarding children. See, e.g., CAL. FAM. CODE § 3020 (West Supp. 1995) (stating that “it is the public policy of this state to assure that children have frequent and continuing contact with both parents after the parents have separated . . . and to encourage parents to share the rights and responsibilities of child rearing . . . “); Stanley v. Illinois, 405 U.S. 645, 649 (1972) (holding that a non-custodial father cannot be presumed unfit as a parent without proper notice and hearing); Lusker v. Guardianship of Bena Christine Lusker, 434 So. 2d 951, 954 (Fla. Dist. Ct. App. 1983) (explaining that a mother’s dying wish for a guardian nominee was overruled by the father’s late objection).
207. Laura Jimenez, Living With HIV, Living for My Son, in ORPHANS, supra note 3, at 51.
her meet the needs of the entire family. She must feel that the service providers both respect her privacy and care about the welfare of the entire family.

The proposed Federal Standby Guardianship Act can be a helpful means of encouraging a parent to plan for the future because the Act enables the parent to see the fruits of her planning efforts. The Act would also allow for a gradual, peaceful adjustment of the family to its future lifestyle by keeping the parent actively involved in the process. Still, the parent's social needs cannot be ignored. As one parent with AIDS who feels "luckier than most" because of starting custody and transition planning expresses: "as much as I try to be unemotional about this, I just hate it that other people are going to have the opportunity to see the things that I should see."

One especially difficult issue for a parent with AIDS is deciding to whom and how to disclose her medical condition. One mother who, at a counselor's suggestion, disclosed her condition to her children, regrets doing so. Her children, two teenagers and a grade-school child, are now in denial and refuse to discuss her illness or death. Another mother with AIDS equates telling close friends and relatives of her status with "taking control of my life. I'm not ashamed anymore." Disclosure is a highly personal decision, one that each parent must make on her own. "Secrecy also needs to be respected as the way some families cope with AIDS." One innovative program, New York's Informed School Project, assists parents in disclosing their children's HIV status to schools by allowing the par-

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208. Sallie Perryman, Family Concerns about Confidentiality and Disclosure, in ORPHANS, supra note 3, at 70.

209. Id.

210. Pinott, supra note 14, at 84 (concluding that "[w]hen custody planning is in place, parents can go forward, leading their lives and loving their children, knowing that their future is assured").

211. Rosenfeld, supra note 84, at 197 (explaining that "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").


213. Luis Arce, A Father's Story, in ORPHANS, supra note 3, at 49.

214. Waysdorf, supra note 201, at 178 (explaining that "women with HIV and AIDS live with the constant fear that public knowledge of their illness will unleash further isolation, impoverishment, stigma, and hostility from others, directed at themselves and their children").

215. Draimin, supra note 143, at 17.

216. Draimin, supra note 145, at 17.

217. Jimenez, supra note 207, at 52.

218. Dane, supra note 146, at 60-61.
ents to disclose incrementally. Similar programs that honor the parents' feelings and desired pacing of disclosure should be designed to help parents feel more comfortable about accessing much-needed support services. Service providers, working with the entire family, "can help families feel safe to say the word 'AIDS' without looking over their shoulders to see who is listening."**

**b. The Non-Custodial Parent Without AIDS**

While most of the cases discussed in this Article involve single parents with AIDS, non-custodial parental rights remain an important factor in many cases. In the best scenario, a caring non-custodial parent will assume guardianship of the children. Another positive issue is approval of the proposed guardianship by the non-custodial parent. As part of the standby guardianship procedure, each parent should be notified of the petition. By common law, biological parents are the natural guardians of their children, whether they have custody or not. If a non-custodial parent is not notified of the standby guardianship hearing, or if the non-custodial parent objects to the proposed guardianship, the proceeding may be invalid. In this situation, custody may be awarded to the non-custodial parent unless the proposed guardians can show it is in the "best interests of the child" to grant them guardianship over the parent; the parent need not make any showing of fitness in order to gain custody.

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220. Dane, *supra* note 146, at 68.


222. Herb, *supra* note 81, at 90.

223. The common law grants natural guardianship to parents, with the exception of the following circumstances: neglect, abuse, abandonment, or unfitness. Pinott, *supra* note 14, at 78.

224. *See* Lusker, 454 So. 2d at 953 (holding that because the non-custodial parent failed to consent to the standby guardianship petition, the court could not make the custodial appointment).

225. The notification requirement may be waived with a showing of due diligence to notify. *See*, e.g., *Cal. Prob. Code* § 1260(b) (West Supp. 1995). In addition, the relevant statute delineates the non-custodial parent's rights in a joint guardianship hearing: "[appointment of a Joint Guardian] shall not be made over the objection of a non-custodial parent without a showing that the noncustodial parent's custody would be detrimental to the minor, as provided in Section 3041 of the Family Code." *Cal. Prob. Code* § 2105(f) (West 1994).

The proposed guardians cannot gain custody over the non-custodial parent unless they show the non-custodial parent to be unfit and themselves to be the guardians in the best interests of the child. *Stanley*, 405 U.S. at 649. This burden of proof placed on the proposed guardian, faces a strong presumption in favor of preserving the traditional family unit and recognizing the time-honored natural parental rights of biological parents. *See*, e.g., *Cal. Fam. Code* §
For instance, in *Lusker v. Guardianship of Bena Christine Lusker*, appellant-father opposed the lower court’s appointment of his now-deceased wife’s designated standby guardians. The appellate court permitted the father to challenge the confirmation of standby guardianship, although the father did not contest the order within the statutory time limit of thirty days. The mother died two months before the trial court confirmed the appointment, but the appellate court ruled that after her death, the father was the natural guardian. Citing the “strong public policy favoring the natural family unit,” the appellate court put the burden of proof, a “clear and convincing” standard, on the non-parent. Although the mother attempted to plan for her children’s future care, the appellate court found that this could not be an exclusive decision; both parents’ rights must be respected. In order to avoid a holding similar to *Lusker*, attorneys working with mothers whose former partners are absent must alert mothers to the notification requirements and possible legal consequences of not communicating with the non-custodial parent.

3. Potential Guardians: Relatives and Friends

As highlighted above in the discussion of *Lusker*, guardianship can be a hotly contested procedure. While all potential guardians must meet certain criteria to be legally permissible, the parent with

3020 (West Supp. 1995) (“[I]t is the public policy of this state to assure that children have frequent and continuing contact with both parents after the parents have separated . . . and to encourage parents to share the rights and responsibilities of child rearing . . .”).

While the parent with HIV/AIDS is still alive, however, her/his infected status is not recognized as grounds for a custody change favoring the healthy non-custodial parent. Sparing the child(ren) the experience of watching their parent die from the disease is also not seen as legitimate grounds for awarding custody to the non-custodial parent. Geballe, *supra* note 4, at 146.

226. *Lusker*, 434 So. 2d at 951.
227. *Id.* at 954.
228. *Id.* at 953.
229. *Id.* at 954.
231. *Id.* (explaining that the Florida standby guardianship statute “requires the petition or consent of both parents”).
232. *Id.*
233. *Id.*
234. *Id.* (holding that the petition for guardianship could not be granted because the non-custodial parent did not consent. Had the mother notified the non-custodial father and obtained his consent, the court could have appointed the pre-selected standby guardians).
235. *Lusker*, 434 So. 2d at 951.
AIDS ultimately designates the prospective guardian in a joint or standby guardianship proceeding. The choice of guardian may touch off old hostilities centering on the parent's disease or ignite custody disputes after the death of the parent. Relatives may be upset by the designation of a friend, and vice versa. These situations, however, only occur where more than one potential guardian wants to assume care of the children.

In many cases, the parent with AIDS wonders who can be solicited to fill the guardian role. In one case, a father and mother, both infected along with their three young children, could only turn to the father's mother. The grandmother recalls her shock at learning that her grandchildren were HIV-positive and in contemplating her estranged son's request: "I was left with a heavy burden. I knew nothing about AIDS. All I knew was that it was a hideous disease and nobody wanted to get involved in it."

Despite these concerns, the grandmother accepted her son's entreaty. After three court appearances, she became the guardian of her grandchildren. A few months later, when the children became symptomatic, she went back to court and the judge realized she had not been given government benefits to which she was entitled for the care of the children. Five years from that time, she was finally able to adopt the children. Her story reflects a general lack of support services and information regarding what assistance is available to guardians. She summarizes her experience as a guardian dealing with her grandchildren's condition as "a mean, hideous disease and a 24-hour situation. You never know when or how a child is going to get sick, or what to expect. You just do not know. You must have patience and love, and you have to give out a whole lot of good en-

239. Lusker, 434 So. 2d at 951.
240. Draimin, supra note 143, at 22 (commenting that "the greatest barrier to custody planning is the unavailability of a new guardian").
241. Setal, supra note 238, at 41.
242. Setal, supra note 238, at 41.
243. Setal, supra note 238, at 42.
244. Setal, supra note 238, at 42.
245. Setal, supra note 238, at 43.
246. Setal, supra note 238, at 45.
247. Waysdorf, supra note 201, at 195 (explaining that guardians "lack access to desperately needed psychological services, such as counseling, physical and speech therapy and respite care." In addition, "no organized system exists to provide [guardians] support services, such as counseling, liaisons to schools, transportation, and access to affordable housing.").
For the guardianship to be successful, the prospective guardian must understand his or her new role. Service providers with knowledge and experience in this area are invaluable to prospective guardians. Social workers and case managers maintain contact with the children as they work with the family. They can alert guardians to the children’s needs and assist guardians and children with effectively communicating in their new roles. Providing this support ensures that the family can work together and achieve the stability and warmth envisioned by the parent who designated the guardian.

IV. CONCLUSION: THE NEED FOR NATIONAL ENACTMENT OF THE STANDBY GUARDIANSHIP ACT TO EMPOWER HIV/AIDS-AFFECTED FAMILIES

The pace of the AIDS epidemic refuses to dwindle. As the disease spreads, more and more families with children are affected. Our social support systems must adapt to the needs of HIV/AIDS-affected families. An important step has already been taken in several states with separately enacted guardianship laws, but federal legislation is required to ensure that all families affected by HIV/AIDS may benefit from the advantages of a standby guardianship.

Despite legislative efforts by several states, the implementation of standby guardianships is not as widespread as it should be. As of yet, there have been no systematic studies of the efficacy of the individual states’ efforts. However, the general response of service providers and the families who benefit have been overwhelmingly positive.

248. Setal, supra note 238, at 46.
249. “Both the new guardian and the surviving children are concurrently dealing with change and loss.” Barbara Draimin, A Second Family? Placement and Custody Decisions, in FORGOTTEN CHILDREN, supra note 3. Housing, integrating the children into a new family with new rules and expectations, and finances are concerns of all new guardians. Id. at 135-36.
250. Draimin, supra note 143, at 20 (stating that “[s]upport networks for these . . . guardians of these affected youth are urgently needed”).
251. Pinott, supra note 14, at 84.
252. David Michaels & Carol Levine, Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States, 268 JAMA 3456, 3458 (1993) (concluding that “by the year 2000, the overall number of motherless children and adolescents [from HIV/AIDS] will reach 82,000,” a sharp increase from the estimated 45,700 orphaned by the disease through 1995).
253. Interview with Virginia Weisz, Directing Attorney, Children’s Rights Project of Public Counsel, in Los Angeles, Cal. (Nov. 2, 1995). As of yet, nation-wide longitudinal studies are nonexistent. However, four recent studies show that in states with joint guardianship or standby guardianship laws, legal custody planning was occurring more frequently but informal arrangements continued. Draimin, supra note 249, at 127-30.
254. See generally supra note 182 and accompanying text; Pinott, supra note 14; Herb, supra note 81; Symposium, supra note 34; Draimin, supra note 249.
Service providers must inform parents with AIDS of all of their legal options. Greater awareness among service providers of what the Federal Standby Guardianship Act can offer a parent with AIDS, such as certainty of future care with the continued ability to be a parent, will lead more parents to recognize the benefits of establishing such guardianships. The Standby Guardianship Act focuses on the best interests of the child by ensuring a smooth transition to future care while it empowers terminally ill parents to establish a guardian with legal endorsement.

Despite its significance, the proposed Standby Guardianship Act cannot be viewed as the single solution for parents with AIDS. Social workers, case managers, and other support service providers must coordinate efforts to meet the social as well as legal needs of HIV/AIDS-affected families. Initiating a plan for her child’s future when she knows she will not share in it is a difficult decision for a mother to make; legal and social counseling may be required for her to contemplate and begin future planning. It may take time to recognize that the Standby Guardianship Act can help her realize her long-term interest in the court honoring her designated guardian. As one mother with AIDS declared, “[h]elping women is the best way to help their children. HIV-positive women with children need support groups and psychiatric help. They also need financial and legal assistance. They need love and understanding from their families and communities.”

While the Standby Guardianship Act would certainly assist in the child’s smooth transition from parent to guardian, the law cannot succeed in isolation. The child will undoubtedly have many questions and concerns that a service provider, ideally with the child’s parent, will address. School personnel must also be sensitive to any special needs of the child. The prospective guardian, given the opportunity to foster a relationship with the child while the mother is alive, may need further support when she or he embarks on the new role of sole guardian. With access to support services, these families can enjoy the full benefits facilitated by the Federal Standby Guardianship Act.

255. Jimenez, supra note 207, at 52.