



Abandoned Infants Assistance
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Standby Guardianship

Definition of Standby Guardianship

The purpose of standby guardianship is to allow parents, who have chronic, debilitating, or terminal medical conditions or illnesses, to make care and custody plans for their children now that will become effective at some future date (Simms, 1996).

A standby guardian is chosen by a parent to become the legal guardian of the parent's minor children, in the event the parent becomes unable to care for the children. In general, the standby guardian becomes the active caretaker of the children after either:

- 1) the death of the parent;
- 2) the parent becomes mentally or physically incapacitated; or
- 3) upon the request of the parent (Pinott, 1994).

Without standby guardianship, the range of legal options available to ill parents to plan for the future care and custody of their children is inadequate (Waysdorf, 1994; Levine, 1995; Mellins, 1996). These options include informal arrangements, a Will, power of attorney, transfer of guardianship, foster care and adoption (HIV Law Project, 1994). Informal arrangements, though common, provide the new caregiver with "no legal relationship to the child and no legal authority to make decisions in the child's behalf" (HIV PPNews, 1998, p.1). A signed Will or power of attorney designates a guardian to take care and custody of the children only after the death of the parent. Transfer of guardianship, foster care and adoption require a parent to immediately relinquish care of the children (FCAN, 1995; Building Bridges, 1996).

Standby guardianship provides a middle ground. Waysdorf (1994) explains: "standby guardianship allows for the immediate transfer of custody upon the parent's incapacity, permits retention or sharing of parental rights, and then establishes permanent guardianship after the parent's death" (p. 206). Standby guardianship also helps to protect the psychological and emotional health of the family. Standby guardianship can "reduce stress for both the parents and the children, provide some semblance of family stability, and provide a way to support the child during the family transition" (Mellins, 1996, p. 143).

The Need for Standby Guardianship

Thousands of children are orphaned every year due to the death of a parent from an illness or another medical condition (Levine, 1994). In the United States in 1997 (Centers for Disease Control [CDC], 2000), the last year for which statistics are available, over 30,000 women between the ages of 18 and 45 died due to illnesses or other medical conditions.

20 leading causes of death, U.S., 1997, all races, females, 18-45. (CDC, 2000)

Malignant Neoplasms	13884
Heart Disease	5719
HIV	2741
Cerebro-vascular	1962
Liver Disease	1372
Diabetes	1177
Pneumonia/Influenza	917
Bronchitis/Emphysema/ Asthma	753

Congenital Abnormalities	587
Septicemia	499
Benign Neoplasms	304
Nephritis	297
Viral Hepatitis	253
Anemias	203
Hypertension	125
Total	30793

Many more children will be orphaned due to illness every year. HIV infection provides a good case study, as the possibility of losing a parent to AIDS continues to be very real. Although there have been considerable advances in medical treatment, HIV is still a chronic, debilitating, and an almost universally fatal illness (Pediatrics, 1999). In fact (Miami Herald, 2000), Florida reported an increase of 5% in deaths due to AIDS in 1999 compared to 1998. This was the first increase in the number of people dying from AIDS in Florida since 1995 (Ft. Lauderdale Sun-Sentinel, 2000).

The CDC (1999) reports that as of the end of 1998 there were almost 60,000 women in the United States living with AIDS. It is estimated that 250,000 women are infected with HIV, and the number of AIDS cases and HIV infections among women continues to increase every year (Selbin & Del Monte, 1998). Most of these women have at least one child and “many have two or more dependent children for whom they are the primary provider” (Selbin & Del Monte, 1998, p.115). In addition, approximately 6,000 - 7,000 children are born annually to women with HIV (Lindegren et al., 1999).

Protecting the Welfare of Orphans of Illness

In planning for these orphans of illness, finding new, safe and permanent homes is a priority (Levine 1994). Permanence for children is the central component of child welfare legislation. As explained in *Adoption 2002: The President’s Initiative on Adoption and Foster Care Guidelines for Public Policy and State Legislation Governing Permanence for Children* (Duquette, 1999):

The concept of permanency has assumed a central place in American child welfare law and policy because permanency establishes the foundation for a child’s healthy development. The basic needs of children include safety and

protection; a sense of identity; validation of themselves as important and valued persons; stability and continuity of caregivers; an opportunity to learn and grow cognitively, physically and emotionally; and a protected custodial environment that is legally secure. Permanency, as epitomized by a safe, stable relationship with a nurturing caregiver, allows these basic needs to be met. (p.3)

Adoption 2002 (Duquette, 1999) also describes the hierarchy of permanence. For children who cannot remain with their natural parents, adoption and legal guardianship provide the most assurance of safety and permanence. In addition, priority should be given to assisting the children to remain within the family’s kinship network. Informal arrangements are not preferred, as the caregivers do not have legal standing. These arrangements may create difficulties for the caregiver and children in obtaining public benefits, and in interacting with schools and medical facilities. Foster care is temporary and should be used only if no permanent option is available.

In this context, standby guardianship provides a method for establishing permanence. While they are still well, parents can make a specific plan for the future care and custody of their children. Through standby guardianship, parents “have continued custody and control of their children for as long as their health permits, while facilitating transition to guardianship after they die” (Levine, 1995, p. S60).

National Support for Standby Guardianship

As a method of providing permanence for children and assisting families affected by terminal illnesses, standby guardianship has garnered wide support. The federal government adopted a strong position in favor of all U.S. states enacting standby guardianship legislation. The *Adoption and Safe Families Act* (1997) reads:

It is the sense of Congress that the States should have in effect laws and procedures that permit any parent who is chronically ill or near 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 the consent of the parent. (Sec.403)

This position was reiterated in Adoption 2002: The President's Initiative on Adoption and Foster Care Guidelines for Public Policy and State Legislation Governing Permanence for Children (Duquette, 1999): "We recommend that State statutes provide for the legal option of Standby Guardianship, which allows a chronically or terminally ill parent to authorize another adult person to serve as guardian of a child when the parent dies or becomes temporarily or permanently incapacitated" (p.6).

In addition to the federal government, the child welfare, legal and medical communities have all stated their support for standby guardianship legislation. Beatty and Hershfield of the Child Welfare League of America (1995) stated, "As the HIV epidemic threatens to leave a growing number of children parentless, it is more important than ever for child advocates to advance standby guardianship as a planning option for families in all states" (p. 9).

In August 1995, the American Bar Association stated its support for:

...action by federal, state, territorial and local governments to create legal mechanisms that allow people with HIV, AIDS or other debilitating, chronic, fatal illnesses to better plan for long-term care for themselves and their families, including standby guardianships, advance medical directives, and viatical statements. (Samerson, p. 28)

The American Academy of Pediatrics also supports the development of standby guardianship laws. In February of 1999, they stated their position:

Pediatricians should advocate for state laws that include provisions to authorize flexible and standby guardianship and that provide specific funding to facilitate planning for children with parents with HIV/AIDS who will become ill and have a limited life expectancy. (p. 510)

Overview of Current Legislation

As of August 2000, legislation to assist a parent in making future care and custody plans has been enacted in twenty states: Arkansas, California, Colorado, Connecticut, Florida, Illinois, Iowa, Maryland, Massachusetts, Minnesota, Nebraska,

New Jersey, New York, North Carolina, Ohio, Pennsylvania, Virginia, West Virginia, Wisconsin, and Wyoming (State Codes).

Although there are differences between the states, most of the current standby guardianship laws have several components in common:

1. The statutes allow a parent or a legal guardian to appoint a standby guardian for the minor children. Some states require that the parent be at risk of death or incapacity due to an illness or a medical condition; others, such as Illinois, do not.
2. The events that trigger the activation of the standby guardian include the death or the incapacity of the parent or legal guardian. Some states also allow the parent to consent to a transfer of guardianship at any time the parent feels is appropriate.
3. The states set forth the procedure for a parent or legal guardian to petition the court for judicial appointment of a standby guardian. A court hearing is then held regarding the petition. Most of the states also allow a parent or legal guardian to designate a standby guardian in writing. After the death or incapacity of the parent or legal guardian, the designated standby guardian must notify the court of the triggering event, file a petition for guardianship, and participate in a court hearing to be appointed legal guardian.
4. The states require that the court be notified about a triggering event within set time limits. If a judge has appointed the standby guardian, few states require an additional court hearing.
5. If a standby guardian becomes active due to parental incapacity, the laws allow for the restoration of parental authority upon the improved health of the parent. The guardian resumes standby status.
6. The statutes allow the parent to revoke the standby guardian agreement at any time.
7. Unless a non-custodial parent's rights have been terminated, all of the statutes require that the non-custodial parent must be notified of the standby guardian proceedings; either at the initial court approval or when the standby guardian provides proof of a triggering event and requests legal guardianship (Larsen, 2000; ABA, 1999; State Codes).

Although similar in intent to the other states, future care and custody legislation in California and Connecticut is somewhat different.

California allows the appointment of a co-guardian, rather than a standby guardian. This law allows a:

Parent with a terminal condition to be able to make arrangements for the joint care, custody, and control of his or her minor children so as to minimize the emotional stress of, and disruption for, the minor children whenever the parent is incapacitated or upon the parent's death, and to avoid the need to provide a temporary guardian or place the minor children in foster care, pending appointment of a guardian, as might otherwise be required. (California State Code, Probate Code Section 2105)

Connecticut allows for both standby guardianship and co-guardianship.

Standby Guardianship in Practice

There has been little research on the utilization and efficacy of standby guardianship. The small amount of research that is available focuses on parents with HIV and AIDS orphans, and suggests that standby guardianship is underutilized.

In 1995, Draimin reviewed four studies and found that most, if not all, parents with HIV are concerned about the future care and custody of their children. However, most parents appear to rely on informal arrangements with family members, and few parents follow through on making a formal, legal care and custody plan for their children. For example, a study by the Division of AIDS Services and the Orphan Project in New York City found that only 24 of 43 families had any kind of documented future care and custody plan. Of these 24 families, "only 8 had utilized the assistance of legal services in drawing up documents formally naming the selected person as the new guardian, and none had gone to family court..." (p.128).

In a study of 151 parents with HIV, Rotheram-Borus (1997) reports that 81% of mothers and 75% of fathers initiated future custody discussions with family and friends almost immediately after being diagnosed with HIV. For a majority of children (75.9%) in the study, parents had spoken to a potential future caregiver, and 99% agreed to care

for the children. In contrast, only 24% of parents had discussed this same issue with social service staff, and only 30% had initiated legal planning.

Forehand et al. (1998) found that of 25 HIV positive mothers, only 35% made any legal plans for their children before the mothers died. Forehand et al. (1998) also reports on a similar 1998 study by Boxer et al. that "found that in only 25% of the cases were legal custody arrangements established prior to the mother's death" (p.716).

Obstacles to the Utilization of Standby Guardianship

Since most states do not have standby guardianship legislation, many parents do not have the option to appoint a standby guardian for their children. In the states with standby guardianship, several obstacles contribute to underutilization. These obstacles can be largely grouped into two areas: emotional and systemic. Resistance to thinking about dying and reluctance to involve a non-custodial parent are two of the emotional barriers. Systemic barriers include lack of or misinformation about planning, and complex and insensitive legal and child welfare systems (Casey Family Services, 1999).

The emotional stress of living with HIV or another terminal illness has been well documented (Jenkins, 1996). Parents have the additional worry about their children. Along with the fear of their own deaths, there is the realization that they may not see their children grow up (Mason, 1998). This realization can be too painful to cope with for some parents. As Taylor-Brown (1998) explains, "some parents may never be able to designate a guardian because the task is simply too emotionally challenging" (p.352).

All states with standby guardianship legislation require that a non-custodial parent be notified about the request to appoint a standby guardian (ABA, 1999; State Codes). Most states assume that the non-custodial parent will take over custody and guardianship of the children, and require extensive efforts by the custodial parent to locate the non-custodial parent. This is true even when the non-custodial parent has had little or no contact with the children, and has not contributed in any way to the raising of the children (McConnell, 1995).

This requirement and the underlying assumption may prevent a custodial parent from making a formal permanency plan and appointing a standby guardian. A study done at Montifiore Hospital in New York City (Casey Family Services, 1999) interviewed 200 mothers with HIV, who had a total of 378 children. Most of the mothers reported that the children's fathers had little or no involvement with the children, and few of the mothers wished to involve the children's fathers in future care or custody planning. The study found that the women feared: "(1) giving the father an opportunity to take the children away from them, (2) re-initiating contact with someone who may have been abusive in the past, or (3) alerting the father to a custody agreement he may not like and therefore increasing the chance he will contest the plan" (p. 121).

Fear of working with the family court and child welfare systems may also hinder formal future care and custody planning. Parents may lack knowledge about the range of permanency planning options available, including standby guardianship (Taylor-Brown, 1998). They may also not know to whom to turn to get this information or who is available to provide legal services (HIV PPNews 1997).

The standby guardianship process itself can be complicated and daunting. In their *Best Practices for Standby Guardianships* (Ambia et al., 1998), a group of service providers in New York City detailed problems faced by parents in setting up a standby guardian. Parents and potential standby guardians were often treated as if they were under investigation for child abuse and neglect. Despite the fact that the court was not required to investigate the homes of potential standby guardians, in practice home investigations were routinely done on both the standby guardian and the petitioning parent. In addition, clerks and judges routinely requested additional documents and hearings that were not required by the standby guardianship legislation, and which delayed the proceedings and unnecessarily invaded the privacy of the petitioner and standby guardian.

Because of the difficulties involved in going to court and getting a judicial appointment, parents who do make future care and custody plans often prefer to designate the standby guardian in writing; rather than to go to court (Casey Family Services, 1999). This puts the onus on the standby guardian to go to

court, after the death or incapacity of the parent, and petition for guardianship based on the written designation. The disadvantage being that a full court hearing will not be "held during the parent's or legal guardian's lifetime, when the parent or legal guardian is available to give testimony as to why the proposed standby guardian should be appointed" (HIV Law Project, 1994, p.11).

Due to these obstacles, most terminally ill parents either develop no future care and custody plans for their children or rely on informal agreements with relatives and friends (Draimin, 1995; Forehand et al., 1998). Orphans of illness are often left in limbo, with no specific or legal plan to provide for their safety and permanence (Levine, 1995; Taylor-Brown, 1998). Addressing these obstacles and promoting the use of standby guardianship is a key element in establishing permanence by legalizing the relationship between the new caretakers and the children (Mellins, 1996; Geballe, 2000).

Overcoming the Obstacles to the Utilization of Standby Guardianship

Because of the emotional and social complexity associated with future care and custody planning, assisting a parent in utilizing standby guardianship, or in making any kind of estate plan or advanced directive, requires a continuum of services. At a minimum, this continuum should include medical, mental health, case management, and legal services (Taylor-Brown, 1998; Selbin & Del Monte, 1998). Medical services should be available to treat the parents' illnesses. Mental health services for parents should address the emotional difficulty of living with a terminal illness, of preparing for the possibility of death, and of the need for the children to have a safe and permanent home. Children may also need counseling to cope with the loss, or potential loss, of their parents (Taylor-Brown, 1998). As most parents are simultaneously coping with many problems, case management services are needed to provide assistance with concrete needs, including housing, income support, and child care (Selbin & Del Monte, 1998). Legal services should detail the range of permanency options for the family, assist with the completion of the future care and custody plan, and advocate to ensure the activation of the plan (Selbin & Del Monte, 1998). Service providers should be knowledgeable about the legal and bio-psycho-social issues involved, and

work cooperatively to help provide for the safety and permanence of children whose parents are terminally ill (Retkin, 1997). Ideally, service providers would be located together, to provide maximum accessibility and continuity of care (Selbin & Del Monte, 1998).

Special consideration should be paid to the needs of single parents with terminal illnesses. According to the U.S. Bureau of the Census (Lugaila, 1998), in the United States, 27.7% of all children under the age of 18 live with only one parent. For many families, the immediate answer to who will care for the children after the death of one parent is the other parent. Unfortunately, this is not always possible. For a variety of reasons, the other parent may be unable or unwilling to become the caretaker for their children (McConnell, 1998). For example, most families affected by HIV consist of a mother with one or more children. In many cases, the fathers have never been involved with the care of the children (McConnell, 1995). Although the non-custodial parent may not have lost parental rights, most mothers with HIV prefer to have a close family member appointed guardian, particularly one who already has a good relationship with the children (Casey Family Services, 1999).

In deciding with whom the children should live after the parent's death or incapacity, the custodial parent's choice should be recognized as being in the best interests of the children. With this assumption, substantial weight should be given to the custodial parent's choice for standby guardian (Ambia, 1999). Judicial appointment of the custodial parent's choice for standby guardian is not tantamount to terminating the non-custodial parent's rights to the children. The non-custodial parent does not lose legal rights or standing in family court (McConnell, 1998).

The assumption that the custodial parent is acting in the best interests of the children should also strongly inform the court processes of appointing and activating a standby guardian. Family court hearings, paperwork, and other administrative details should be streamlined. Standby guardianship laws should be designed and implemented such that they "encourage parents to come forward and plan for their children's care early in their illness" (Ambia, 1999, p.1).

Conclusion

Effectively assisting parents who have chronic, debilitating, and fatal illnesses or medical conditions in making future care and custody plans for their children requires the development of flexible permanency planning options, such as standby guardianship. Standby guardianship legislation, in intent and implementation, must recognize the unique situation of ill parents and acknowledge that, in making future care and custody plans, the parents are acting in their children's best interests. In practice, providing a continuum of services for the children and parents is key to facilitating the utilization of standby guardianship. At a minimum, these services should include medical treatment, legal assistance, mental health counseling, and case management.

Unfortunately, most states do not allow standby guardianship as an option for future care and custody planning. Even where standby guardianship is available, "few states have established multidisciplinary programs that help parents take full advantage of the new guardianship options. Few have even begun to address the complex needs of the 'second' families. Few have developed plans to meet the needs of the older AIDS-affected youth" (Geballe, 2000, p.407).

Creating laws and developing multidisciplinary services that promote the safety, well-being and permanency of orphans due to parental illness are important challenges for legislators and for providers of mental health, medical, legal and social services. Discussing this challenge in an April 2000 article, Geballe issued a call to action to meet the needs of children and families affected by terminal illness:

How well we ensure the quality and continuity of parental care for children whose parents are living with HIV and AIDS, or who later die of it, is one of the tests of our generation. If we fail to meet this challenge, we are knowingly placing thousands of children and youth at enormous, predictable, and potentially fatal risk. (p.407)

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Wisconsin Statutes, Chapter 48, Section 48.978 - 48.978(2)(c) 1.f.

Wyoming Statutes, Title 3, Chapter 3, Article 3, Section 3-3-301.

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