Who Will Care for the Children?
Unwinding The Legal Maze

As we enter another year of the AIDS epidemic, women of child-bearing age have become the fastest growing segment of persons with AIDS. Government statistics published in 1993, report that HIV infection in women has increased dramatically and is considered the fourth leading cause of death among women ages 25 to 44 years (Centers for Disease Control, 1993). In 1993, HIV infection among women increased 9.8% compared to 2.5% in men (Selik & Buehler, 1993).

As the number of women who are infected with HIV rises, we see a corresponding increase in the number of children who are directly affected by this disease. Because studies of family structure demonstrate that women are the sole and primary caregivers for the vast majority of children and youth, these figures become especially alarming (Michael & Levine, 1992). When these women die, they leave behind children who require shelter, food, medical care, and emotional support. By the year 2000, it is estimated that 125,000 children will be left motherless by this epidemic (Geballe, Gruendel & Andiman, 1995). AIDS will leave more children motherless than motor vehicle accidents or cancer (Michael & Levine, 1992). As more and more women are diagnosed, the question arises, who will care for the children?

Those who are living with HIV are constantly faced with uncertain thoughts of the future and, especially, the future of their children. Many fear the myriad of legal mazes they must traverse to find a safe and secure home for their children. A large number of women who die of AIDS fail to name a caretaker, and 53% of parents living with AIDS have no viable plan for their adolescents (Levine & Stein, 1994). Lack of planning results from several factors, including lack of formal legal advice or knowledge (Nicholas & Abrams, 1992). For example, many believe that informal kinship care is a reasonable option. Placing a child with a relative may be the easiest approach and, with appropriate legal arrangements, most beneficial to the child. Without proper legal arrangements, however, the relative may not be eligible to receive public benefits or assistance, and will not be able to enroll the child in school or consent for medical care. Because of a child's many needs, legal arrangements are imperative. It is important, therefore, to educate and empower parents regarding permanency planning options (e.g., wills, adoption, and different forms of guardianship) to alter the silent legacy of these children. Following is a brief description of legal options that may be available to families.

Wills

A will is a legal document used to record a parent's wishes upon her death. A will may include a nomination of a caretaker who will serve as a child's future guardian (primary legal caretaker). The drafting of a will is a relatively simple process that can be done with some haste, and allows a parent to retain full legal custody of her children until her death. A will memorializes a parent's desire for the care of her children. It does not, however, guarantee placement with the parent's chosen guardian. Following a parent's death, the guardian named in the will must petition the court on his or her behalf. The court then determines what it believes to be the best placement for the child. If there is a surviving biological parent, he or she will have to consent to the nominated guardian. The surviving parent will usually be successful if he or

“Parents who are considering placement options for their children should take into account what is available in their state, and what is the best option for them, their children, and the future caretaker.”

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she wishes to seek full custody following
the custodial parent’s death.

A will, therefore, is not binding for
final determination of arrangements for a
child; it only indicates a preference. There
may be a significant lapse in time from the
parent’s death until the guardianship can
be completed. During this time the
children will have no legal caretaker.

Adoption

Adoption is the placement option that is
considered the most permanent. In an
adoption, parental rights are terminated
and transferred to the adoptive parents.
Giving up one’s rights as a parent is emo-
tionally traumatic and may not be a viable
choice for many.

Adoption may also be a financial
hardship for foster parents who plan to
adopt because, following the finalized
procedure, foster care payments are termi-
nated. Most families will be eligible for
some adoption assistance payments, but
these will generally be lower than the
foster care payments they had been receiv-
ing. Children who have “special needs”
that their adoptive families cannot meet
will qualify for Federal adoption assis-
tance, additional benefits (e.g., Medicaid
under Title IV-E or SSI), or state adoption
subsidy programs.

To initiate an adoption, an application
or petition must be completed and filed
with the appropriate court. The petition
requires a signed document from both
parents giving up their rights over the
child. A hearing will then be scheduled, at
which time a judge makes a final determi-
nation. This process can take up to a year
or more. Because of its time and perma-
nence, adoption is impractical and emo-
tionally unfeasible for many parents living
with AIDS.

Guardianship

Guardianship is a less permanent place-
ment than adoption and usually a more
plausible choice for parents. It involves a
process in which a parent’s rights are sus-
pended, thereby allowing the legal
guardian to serve as the primary caretaker.

A petition must be filed, and a judge
makes a final ruling after a hearing several
weeks later. In the interim, a court-man-
dated social worker will visit the prospec-
tive guardian’s home for a complete home
assessment. If there is a surviving parent,
he or she must either consent to the place-
ment, abandon the child or waive his or
her rights, in order for the placement to
proceed. Surviving parents who challenge
the appointment of a nominated guardian
may succeed, unless demonstrated to be
unfit. At the time the guardianship order is
signed, all parental rights are suspended.
From that point on, the guardian has legal
authority and will not have to take any
steps following the parent’s death.

Although this fairly simple procedure
allows a parent to complete the process of
finding a home for her children before her
death or disability, she must relinquish
her decision-making authority of her chil-
dren and, sometimes, physical custody, as
well. Also, if a child moves in with a for-
mal guardian, the child will generally
be removed from the parent’s entitlement
benefit, leaving the parent with a dimin-
ished income. At the same time, legal
guardians are typically ineligible to
receive foster care benefits. Guardianship,
for these reasons, may still not be a pre-
ferred arrangement. Many women, there-
fore, attempt to wait until the last minute
to make these guardianship arrangements,
but they risk becoming too ill to complete
the process. Once again if this process is
not completed the child will have no legal
caretaker and may end up in the foster
system or in legal limbo.

Los Angeles has the second highest
cumulative incidence of AIDS in the
nation. The Los Angeles County Depart-
ment of Health Services report that over
27,000 cases have been confirmed in
Los Angeles county since 1981. The
Alliance for Children’s Rights, the only
free legal services organization in Los
Angeles devoted solely to children, in
collaboration with The Los Angeles
Pediatric AIDS Network, the principal
provider of medical and social services
to children infected/affected by
HIV/AIDS, have developed the Los
Angeles Pediatric AIDS Legal Services
(LA PALS) in response to this unique
population.

LA PALS was established to
ensure that children infected or affected
by HIV/AIDS in Los Angeles County
have access to specially trained attor-
neys who will represent the individual
child. The attorneys may provide assis-
tance in accessing a range of public,
medical, and social services, including
Medi-Cal, supplemental social security
income, social security survivor ben-
efits, and special education. Attorneys
may also assist in cases of children who
have a parent that has either died of AIDS
or is living with HIV/AIDS, who are in
desperate need of legal assistance with
guardianship, joint guardianship, or adop-
tion procedures. LA PALS guides parents
to choose the permanency planning
option they feel is best for them and their
children. When arrangements have been
made for a legal caretaker, parents can
concentrate on caring for themselves
and their children, knowing that their
children’s futures will be assured.

For additional information about
LA PALS, please call Brenda O’Neal,
MSSW, at (213) 368-6010.

The child in the above photo is not a client of
LA PALS.
Joint Guardianship and Stand-By Guardianship

Because guardianship, once completed, automatically suspends a parent’s rights, this generally is not an appropriate arrangement for parents with HIV/AIDS. HIV is an episodic illness. Women who are infected with HIV may have periods where they feel great, intermixed with periods of severe illness. Many of these women would like to initiate permanency planning options but do not want to lose their rights over their children. Several states have lobbied for more sensitive, flexible, and appropriate legal options for parents with a terminal illness. Joint guardianship and stand-by guardianship have been states’ responses to this problem.

Joint guardianship is a permanency planning option available in only a few states, such as California. The primary purpose of joint guardianship is to allow a parent to complete the guardianship process while still healthy, without relinquishing or suspending all of her parental rights. This option enables a parent to choose the legal guardian; allows the child to become familiar with the chosen guardian; and eliminates the uncertainty of the child’s future. (See Lewis and Kent article on p. 11 of this issue.) However, because joint guardianship requires a parent to give up some control of her children by sharing decision making responsibility with the joint guardian, this may not be the perfect solution for many parents. A few states, such as New York, Florida and Illinois, have developed an alternative statute, stand-by guardianship.

Stand-by guardianship allows a parent to complete a process to nominate a secondary individual as a standby to “be empowered to assume the duties of his office immediately on the death or adjudication of incapacity of the last surviving natural parent or adoptive parent of the minor” (Florida Statute, 1991). Stand-by guardianship allows a parent to care for her children when she is able, but upon her death, the legal authority automatically springs over to the stand-by guardian. Under stand-by guardianship, a parent can make legal arrangements while still in good health; be involved with these arrangements through the court process to insure her wishes will be carried out; and retain parental rights until her death. (See Beatty and Hershfield article on p. 8 of this issue.)

Conclusion

While none of the above alternatives may be a perfect solution, joint and stand-by guardianship appear to be the best means of providing for a secure future for the children without eliminating the rights of a parent. Parents who are considering placement options for their children should take into account what is available in their state, and what is the best option for them, their children, and the future caretaker. Parents who attempt to implement any of the above choices should seek the assistance of a legal advisor or legal service center to make the procedure as smooth and easy as possible. There are several community agencies or attorneys who will work with a parent at no cost. With some consideration and planning, parents can help eliminate the uncertainty of their children’s futures and reduce the number of children stranded by this disease.

— Brenda O’Neal, MSSW
Project Manager, Los Angeles Pediatric AIDS Legal Services

REFERENCES


Is This Custody Plan Viable? Ten Questions to Consider

Consider the following hypothetical cases. Marie Johnson learned she was HIV-infected after the birth of her third child. Although she had no symptoms, she began to plan for her children's future—"just to get it off my mind." She signed a standby guardian form designating her sister, who lived in a different city, as the person who would take custody of the children if she were unable to care for them.

Dorinda Stanton, also HIV-infected and also with three children, put off planning until she was seriously ill. Even then she could not bring herself to make a decision. As a result of a family discussion just before her death, her two younger children went to live with her mother, who had cared for them during her illness. Her 16-year-old son went to live with her brother who had two teenage sons.

How can we assess whether these custody plans are viable? That is, are they likely to provide secure, stable, and permanent homes for the bereaved children? It is certainly clear that Marie undertook the better process for assuring that her wishes for her children would be implemented. But unless her sister was willing to take on the responsibility, and had the financial, emotional, and social resources to do so, the plan may have been viable only on paper. Dorinda, on the other hand, did not participate in the ultimate decision about her children's future. But her family, even without much advance discussion, may have chosen the path most likely to lead to stability for Dorinda's children.

Most discussions of custody planning focus on assisting parents through the complex process of deciding whether and when to disclose their illness to family and children, and on the legal options for placing children with the caregiver of their choice. (Although these caregivers are commonly called "new guardians," the term "guardian" technically refers to someone who has been granted that legal status.) Less attention has been paid to the elements of a plan that will influence whether it will succeed in establishing a secure, long-lasting, and nurturing environment for the surviving children.

Very few, if any, custody plans are ideal. Many families affected by HIV are also struggling with many other problems of substance abuse, poor housing, inadequate health care, unemployment, and domestic violence. Disruption and insecurity are common themes in daily life. Custody plans have to be developed within this context, but they should also take into consideration family strengths and resiliency.

Every plan should recognize and respect the parent's deeply held personal values and beliefs, and professionals should not substitute their choices for the clients' wishes. Nevertheless, professionals are not simply technicians to facilitate any and all plans. They have a responsibility to explore with clients what they perceive as potentially negative aspects of plans. In addition, they often explore sensitive aspects of family life (e.g., substance abuse and personal relationships). Maintaining the client's trust while raising questions about potential problems requires both confidence and humility.

This article will consider some of the most common situations that present problems for surviving children and new caregivers. Here are ten questions for parents, social workers, attorneys, case managers, and others who counsel and support parents to consider as part of the planning process.

1. Is the plan intended to be permanent?

The goal of permanency is an ideal, not an absolute prerequisite for viability. The best of plans can go awry for unforeseen and unforeseeable circumstances. But where there are clear indications that the plan is unlikely to be permanent, the next best option may be "serial stability." This concept recognizes that permanency may not be achieved in the initial plan but makes contingency arrangements for the next stage, either by involving a future caregiver at an early point or by sharing responsibilities among caregivers. For example, if the only available caregiver is an older adolescent, an adult should be involved in a supportive role.

2. Will the children be placed in a household where neither the caregiver nor anyone else will subject them to abuse or neglect?

A fundamental consideration is the children's safety. At stake is more than a legal requirement restricting guardianship to individuals who do not have a record of proven child abuse or neglect. It is also important to consider who else lives in the household or is a frequent visitor. Is there anyone who might place the children at risk of physical, sexual, or emotional abuse? If so, even the best-intentioned caregiver may not be able to protect the children.

3. Has the parent discussed his or her serious illness with the proposed caregiver in realistic, not hypothetical terms, and has the caregiver agreed to the plan?

Misunderstandings are common. A parent may have said to a relative or friend, "If something happened to me would you take care of my children?" The conversation may have taken place a long time ago or without any indication that the question was more than hypothetical. The relative might answer quite differently if she understood the imminent nature of the request. A candid discussion of a parent's serious illness (without a precise diagnosis, if preferred) and the practical aspects of implementing the plan will at least assure that the proposed caregiver is informed and consents.
4. Is the caregiver in good enough health to care for the children?

This is perhaps one of the most difficult questions to answer. Many proposed caregivers are themselves HIV-infected or have AIDS; others are older relatives, primarily grandmothers, who may be in poor health because of hypertension, diabetes, heart trouble, or any of a variety of serious conditions that limit their ability to care for young children. Several factors should be considered: who else might be chosen, the degree of disability or limitation, the particular needs of the children, the availability of other family or community resources to provide assistance or respite for the primary caregiver, and the children’s attachment to the caregiver. Some advocates believe that the proposed caregiver’s HIV status should not even be considered, since the disease course is so unpredictable and since raising it as a potential barrier appears to be discriminatory. Others would weigh this factor among others in making a recommendation.

5. Can the caregiver support the children financially, with assistance if needed and available?

Failure to consider the financial responsibilities that accompany placement of children with a new caregiver can undermine the plan’s viability, even if all other factors support the plan. This is particularly true if one or more of the children has special medical or psychological needs or if there are more than three children. Eligibility varies considerably for the benefits currently available to support the children and assist the new caregiver. An experienced counselor can guide the family through the maze of multiple benefit streams and help them determine their best options.

6. To the extent possible, have the children participated in and agreed to the custody plan?

Many parents find it extremely difficult to discuss their illness with their children, much less what will happen in the event of their death. In some cases, although no explicit plan has been articulated, an informal plan has been put into effect, with children spending more and more time with one or another relative or friend (Nagler, Adnopoz, and Forsyth, 1995). Nevertheless, children want to be consulted on such important matters. Mildred Pinott (1993), an attorney with extensive experience in custody planning, points out, “Nothing is more alienating to children than realizing that adults are making decisions about them and around them, but without them” (p. 77). Frequently, children have definite preferences about who they would like to live with and can raise warning flags about potential guardians that parents may have missed. If the custody plan goes before a judge for approval, he or she will ask children over a certain age, usually 14, for their view of the identified guardian. In some cases, the judge may appoint a law guardian to represent the children’s interests.

7. Will the children be placed with their siblings, or at least kept in contact with them?

Sibling relationships are an extremely important element in developing resiliency. In describing her childhood in an orphanage, the author Eileen Simpson (1987) writes, “What I learned from ‘Hansel and Gretel’ was how fortunate these children were to have each other. My greatest piece of luck was to have had Marie as an older sister and companion” (p. 24). Except in special circumstances, siblings (including half-siblings or children who have been raised in the same household) benefit from staying together. This may not always be possible. A large sibling group may have to be separate for practical reasons. Sometimes children who have the same mother but different fathers will be placed with different sides of the family. Even if it is not possible for the children to live together, the new caregivers should be encouraged to keep them in close contact with each other.

8. Does the plan keep the children in familiar neighborhood and school surroundings, or is this not feasible, is there a plan for an orderly transition?

For a child, moving is an extremely stressful event. A national study of the impact of family relocation on children found that moving was associated with an increased risk of children failing a grade and four or more frequently occurring behavior problems; poor children were more likely to move and to experience problems (Wood et al., 1993). In a study of 43 cases at the Division of AIDS Services in New York City, Ivy Gamble of The Family Center found that in over three quarters of the cases, the children had moved after the parent’s death. The moves were almost equally divided among neighborhood, borough, and state. There is no research yet on the combined impact of a parent’s death and relocation, or on the potentially helpful but still stressful effect of moving to a more stable environment. Relocation may be inevitable in many custody plans, but efforts should be made to ease the transition and to recognize the additional stress on children.

9. Does the proposed housing meet basic standards of safety and privacy?

Some custody plans may involve moving a combined family to a larger apartment or house. Most, however, will be based on adapting existing housing to accommodate the new members. In these cases, it is especially important to explore whether the housing plan is realistic and whether it provides basic standards of environmental safety (e.g., adequate plumbing and heating, and freedom from toxic substances). Privacy is also very important, especially for older children, teenagers and children of different genders. Overcrowding is probably one of the most significant stresses on family relationships and can quickly lead to a dissolution of the custody plan.

10. Are there any barriers to legalizing the plan?

In a sense this question includes all the others, as well as some additional ones. For instance, a barrier to a mother’s plan to name her sister as guardian might be the legal rights of the father. Another barrier might be a proposed guardian’s criminal record, even though it was long past and did not involve child abuse. Such barriers are not absolute indications that the plan cannot be implemented, but they represent trouble spots that should be addressed as early and as candidly as possible.

*Please see page 14...*
Until recently, permanency planning for children of mothers with HIV infection might have seemed to some to be a waste of time because of the general consensus that these children had a short time to live. But medically, our society has learned a great deal about HIV and children.

Although we know that, if a child is infected, there is a 25% chance that the child will develop AIDS within one year of birth (Byers, 1993), as many as 70-85% of all children born to an HIV infected mother will not be infected (CDC, 1995). With new AZT treatments for pregnant women, the perinatal HIV transmission rate may be further reduced by as much as two-thirds. Additionally, in one large study, almost 50% of infected children remained relatively healthy at nine years of age (Tovo et al., 1992).

As professionals working with a population that is at risk for HIV infection, we know that permanency planning is of utmost importance for these families. Some of the questions that many people may be struggling to answer regarding planning for this population may include:

- Is permanency planning different for children if they or their families are affected by HIV?
- Can families affected by HIV be reunited if the children were removed from their homes?
- How do you recruit families to serve HIV affected families and children?

Family and Children’s Services of Central Maryland (FCS), a private, non-profit agency, has developed a unique program designed to meet each family’s needs through a continuum of care. This continuum consists of:

- A case management program to help provide families with services in order to keep children out of foster care;
- A treatment foster care program which works toward reunification or relative placement; and
- An adoption component which identifies adoptive resources and expedites the adoption process.

Although many programs offer these services, FCS is unique in its use of foster/adoptive families and the way in which families can move back and forth between the program components.

Continuum of Care

With funding through the FaCT Model Project, FCS offers a case management system to provide ongoing, long term, intensive family services for parents and children impacted by HIV infection. Services include respite care, parenting and HIV education, relationship strengthening, supportive counseling, permanency planning, and transportation assistance.

The second part of the continuum is the treatment foster care program which is currently licensed to serve 18 children affected by HIV/AIDS. The staff consists of: two full-time social workers who provide all clinical services and resource referrals to the families; two full-time case manager assistants who provide coordination and parenting education; and a half-time social worker who recruits and trains foster/adoptive parents.

Lastly, the continuum includes an adoption component which recruits, trains, and identifies adoptive resources for HIV impacted children. The adoption worker is a full-time social worker who also coordinates the adoption and finalization process in order for the family to have consistency, support and more personalized service. Staff from these three program components work together with families to assure permanency for children impacted by HIV**.

Using the Continuum for Permanency Planning

Except for the issue of timing, parents with HIV/AIDS have the same permanency planning choices as other parents. For birth parents who have custody and guardianship of their children, the options include: naming a guardian in a will; filing a guardianship petition in court; filing a custody petition in court; choosing a standby guardian; placing the child in relative care (kinship care); arranging for the child to be adopted; or placing the child in foster care as a temporary measure if no other option is available.
For families involved in the foster care system, there may be fewer choices for permanency planning. Most state regulations give the parents 18 months to change the life situation that brought the child into care. There are cases in which there is pressure to have a child’s plan decided sooner. For some families, their life issues may be too complex to change in such a short time or the parent may be too sick to care for the child on a permanent basis.

To provide another option for these families, FCS recruits individuals and families to become foster/adoptive parents. FCS trains and supports these foster parents to work as a team with FCS staff to return children to their parents and work as mentors and models for the birth parents. If a child cannot go back to a parent, the next step would be to look for a relative to become a resource for the child. The foster/adoptive parent is required to assist in this phase of the permanency plan. If no relatives are identified as suitable, and the child’s plan becomes adoption, FCS asks that the foster family make a commitment to adopt the child, and that the foster/adoptive families continue to have contact with the biological family throughout this process. We know that personal history is important for every person. These continued connections help children keep their history.

FCS has found that some children of HIV infected parents are able to be reunified, and that the possibility of successful reunification is enhanced through the use of case management services and foster/adoptive families. If a child is served by the treatment foster care component as well, FCS’ continuum is like a circle which could be continued if the parent becomes too sick to care for the child.

FCS’ vision is that when a child is reunified, contact with the foster/adoptive family would continue and, if it is needed in the future, the foster/adoptive family would become the respite provider and eventually standby guardian or adoptive resource for the birth family. The belief is that, once connections are made with families, they can be continued and supported by FCS in order to assure permanent families for the children served.

**Recruiting Foster/Adoptive Families**

Recruitment is one of the most important aspects of the program. But before beginning a recruitment campaign, parameters of the recruitment must be determined: Who are you recruiting? Where do these people live? What do they do? Where do they socialize? What will they respond to? A clear definition of the program, including roles and responsibilities

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**NORMA**

In September 1995, Norma will celebrate her seventh birthday. Hopefully on that same day, if multiple bureaucracies cooperate, Norma and her family and friends will also celebrate the finalization of her adoption. At least that is the plan made by her foster, and soon-to-be-adoptive, mother.

In 1989, at six months of age, Norma was placed in a foster home. There was no suspicion at the time that she was infected with HIV. However, during the next six months, she kept getting sick. So, based on her birth mother’s diagnosis, she was finally tested. The positive results of the test were devastating to all those who knew and loved Norma. However, knowledge of her potentially shortened life pushed her foster mother to provide Norma with the best childhood she could. So, when Norma’s permanency plan was changed to adoption in July 1994, it was inevitable that her foster family would now become her adoptive resource.

Through the FaCT Model Project, Norma and her biological and foster families were able to receive more intensive case management and a higher level of services than are normally available within local departments of social services in Maryland. Specifically, the Project funded the following:

- a monthly difficulty-of-care stipend of $200 for the regular foster parent caring for a medically fragile child;
- respite care reimbursement for up to fourteen days per year;
- payment for two summers of gymnastics camp;
- extra pairs of eye glasses not covered by medical assistance;
- private educational testing to identify Norma’s neurological deficits; and
- a timely home study done by the FaCT Model Project’s home study worker.

As part of the FaCT Model Project, the foster care case manager was also able to: enroll Norma in research protocols at the National Institutes of Health (NIH) and accompany her for treatment there; enroll Norma with the Make-A-Wish Foundation so her dream of a backyard pool could be realized; transport Norma to medical and eye doctor appointments; serve as a sounding board and crisis manager for Norma’s foster parent; and intervene between Norma’s foster family and other professionals, e.g., day care providers and pharmacy assistance managers. Additionally, although there was never a plan to reunify Norma with her birth family, the case manager assisted them by: helping Norma’s birth mother locate and make a security deposit for permanent housing; paying her outstanding telephone charges so she could have telephone service; and providing her with a washing machine and some clothing for her four year old uninfected sibling living with her.

Despite these services, there were barriers to Norma’s adoption. The first, of course, was her diagnosis. However, after meeting and networking with other parents of HIV+ children, Norma’s foster mother was able to make a lifetime commitment to her. Since she is a working single parent, however, the double loss of the difficulty-of-care stipend and the daycare reimbursement available to foster, but not adoptive, parents will have a major financial impact on the family. Nevertheless, they have made a family commitment, and everyone who knows Norma is looking forward to her double celebration in September — a new year and a permanent family.

— Donna Plunboff, Foster Home Worker, Baltimore City Department of Social Services.

FaCT Model Project

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**THE SOURCE**

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**VOLUME 5, NUMBER 2**
Standby Guardianship

In direct response to the permanency planning needs of HIV-affected families, several states have recently enacted standby guardianship laws that enable terminally ill parents to designate an individual to serve as their child’s guardian immediately upon the parent’s death or incapacity. Parents are thus able to make a permanent plan for their children without giving up any parental rights until the point that they are unable to provide care. Standby guardianship protects children from uncertain custody determinations while empowering families and giving them a sense of control that is often lost in the face of terminal illness.

Establishing Standby Guardianship

Once a parent decides she* would like to designate an individual to “stand by” as the guardian for her child, most state statutes provide two options for establishing the guardianship. The parent may petition the court for judicial appointment of a standby guardian or may complete a written form designating a standby guardian.

To establish a guardianship by judicial appointment, a parent must file with the court a petition that sets out crucial facts, names the guardian, and designates an event that will trigger the guardianship. Typically, statutes require the triggering event to be either the parent’s physical debilitation, mental incapacity, or death. The court considers the petition, investigates the proposed guardian, and determines whether appointment of the standby guardian is in the child’s best interest. If the court holds a hearing, the petitioning parent may be excused if she is too ill to attend. Once the court grants the petition, the standby guardianship is established and the standby immediately assumes responsibility for the child when the triggering event occurs. The standby guardian then must file with the court documentation — most often a death certificate or physician’s declaration of incapacity or debilitation — of the triggering event. If the guardian fails to file the documentation within the requisite time period, the court will rescind the guardianship.

A parent may choose to fill out a written designation of standby guardianship rather than filing a petition with the court. Most state statutes include the appropriate form, and the parent need only fill in the blanks. Essentially, the parent fills in the name of the standby guardian and the chosen triggering event. She then signs the designation in the presence of two witnesses, who also must sign the form. Once the triggering event occurs, the standby guardian automatically assumes provisional authority for the child for a statutorily defined period of time. During that time, the standby guardian must file with the court a petition for appointment as guardian. Most often, the petition must include a copy of the parent’s written designation and some evidence that the triggering event has occurred. The court will grant the standby guardian’s petition for guardianship if it finds that appointment to be in the best interest of the child.

There are several advantages to both methods of establishing a standby guardianship. The primary benefit of filing a petition for judicial appointment is that the parent can be certain that the guardianship has the court’s approval. If the parent anticipates that someone might contest the appointment, she will be present to testify in court and to advocate for her choice of guardian.

Standby guardianship by written designation might be more attractive, though, to parents who are intimidated by the court system or deterred by a petition filing fee. This method is more immediate, less complicated, and does not require the parent to explain her choice of guardian. She can think about her options privately and fill in the form when she reaches a decision. The disadvantage, though, to using a written designation is that the parent will not be able to advocate for her choice should the guardianship be opposed. In addition, the standby guardian will be burdened with filing a court petition during the often stressful time following a parent’s death or incapacity.

It is important to note that standby guardianship is not an appropriate option for every parent. Because both parents have an equal right to custody of a child, a standby guardianship can never be established if a child’s other parent desires custody and is able to care for the child. Even if this other parent is absent from the child’s life or has abandoned the child, the custodial parent must always attempt to notify the noncustodial parent of her intent to designate a standby guardian. The custodial parent must then show that the other parent does not desire custody of the child and consents to the guardianship — or that the other parent did not respond to notification. Most states will allow the appointment of a standby guardian only if the custodial parent shows that she has made reasonable efforts to notify an absent parent. Some states will also allow the petitioning parent to present evidence that the non-consenting parent is not a suitable custodian for the child.

Advantages of Standby Guardianship

Standby guardianship provides several advantages for HIV-affected families engaged in permanency planning. Most importantly, standby guardianship provides stability for children facing the loss of a parent and lessens the need for foster care. Also, in situations where adoption is the ultimate goal, standby guardianship can provide a gradual, yet safe, transition for children.

The primary legal advantage of standby guardianship is that it allows a parent to make a permanent plan for her child without being forced to relinquish custody or other parental rights. In a traditional guardianship, parents must transfer some of their rights to the guardian at the time the appointment is made. Even if the parent is not yet sick, the guardian becomes the legal caretaker of the child and has the responsibility for making daily decisions.

* For the sake of clarity, all references to gender are inclusive.
about the child’s life. In contrast, a standby guardian assumes authority only at the point that the parent becomes unable to care for the child.

Although a parent can avoid relinquishing parental rights by naming a guardian in her will or other testamentary instrument, the court does not review or appoint the guardian until after the parent’s death. At that time, the parent cannot explain her choice of guardian to the court, and she never knows whether the court approves her plan. Also, the child’s custody will remain undecided during the time period that elapses between the parent’s death and the probating of the will. In contrast, standby guardianship provides a mechanism by which the court can approve the parent’s plan while the parent is still alive, and the parent can be certain that the new guardian’s authority will take effect at the necessary time.

Standby guardianship also recognizes the reality of living with HIV. For example, HIV-positive parents often experience episodic periods of severe illness interspersed with periods of relative good health. Standby guardianships insure that children will be cared for during periods of incapacity or severe illness, but also allow parents to resume care of their children when their health allows. Also, HIV-affected families must contend with the social stigma attached to AIDS, and standby guardianship affords them the opportunity to plan for their children in a more quiet, unobtrusive way.

Although standby guardianship laws are targeted toward families coping with HIV, all parents with terminal illness can benefit from this new planning option. Standby guardianship facilitates an early start in the planning process and encourages parents to begin thinking about other forms of planning, such as living wills or property dispositions.

Existing Standby Guardianship Laws


In 1992, New York enacted a more extensive standby guardianship statute that provided two methods of establishing standby guardianship and included an optional form for written designation. Illinois followed New York’s lead in January, 1994. It enacted a statute that not only provides for designation of a standby guardian but also allows parents to appoint a “short-term guardian” whose authority ends when the parent revokes consent, leaves the hospital, or when the predetermined time period lapses.

Maryland, New Jersey, and North Carolina have all enacted standby guardianship legislation within the past year, and California has enacted a joint guardianship law (Cal. Prob. Code § 2105(f) (1995)) that enables a parent and guardian to share custody of a child (see Lewis & Kent article on p. 11). Several other states, including Georgia (GA H.B. 750), Massachusetts (MA H.B. 5131), Ohio (H.B. 2881), Pennsylvania (1993 PA H.B. 2500), the Standby Guardianship Act), Tennessee (1995 TN H.B. 146), Texas (1995 TX S.B. 907 and 1995 TX H.B. 1709) and Wyoming (1994 WY H.B. 133), have proposed standby guardianship legislation.

Other advocacy efforts have been directed toward federal legislation. Representative Carolyn Maloney (D-NY) introduced H.R. 709, the National Standby Guardianship Act, on January 26, 1995. The bill currently has 31 co-sponsors and has been referred to the House Ways and Means Committee. If passed into law, HR 709 would amend Part E of Title IV of the Social Security Act. The new federal legislation would require states to have laws that would permit a parent who is chronically ill or near death to designate a standby guardian for her child. The bill requires states to have standby guardianship laws in place as a condition of eligibility for federal foster care and adoption assistance funds.

Advocating for Standby Guardianship

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. One advocate has suggested that standby guardianship laws should:

“allow authority to vest in a standby guardian at times of parental incapacity, assure that the authority returns to the parent in times of wellness, preserve entitlements to benefits, allow appointment of a standby guardian after the filing parent has made reasonable attempts to provide notice to the absent parent (though without prejudice to the rights of the absent parent), and require court involvement only in the event of a dispute” (Geballe, 1995, p. 151).

Legislative advocates should also take note of the experiences of other states. For example, the original New

Ohio’s standby guardianship legislation (HB288) passed out of the Ohio House of Representatives on June 16, 1995, with a unanimous vote.
York statute required parents to assert that they were likely to die or become incapacitated within two years of the filing of the petition. After practitioners reported that clients had difficulty making that assertion, the statute was amended in 1994 to delete this provision. Currently, parents in New York may petition for a standby guardian by asserting that they suffer from "a progressively chronic illness or an irreversibly fatal illness..." (N.Y. Surr. Ct. Proc. Act Law §1726 (Supp. 1995)). California is also amending its joint guardianship law to eliminate the requirement of documentation that the parent will die within two years (1995 CA A.B. 1104). In Illinois, legislators have drafted an amendment that would clarify the requisite procedure for notifying parents, guardians, or custodians of pending applications for standby guardianship (1995 IL H.B. 1506, amending 755 ILCS 5/11-10.1). The proposed bill also provides for the court-appointment of a temporary guardian if necessary to protect a child until a formal guardianship can be established.

In states where standby guardianship is already available, efforts should be focused on implementing standby guardianship into existing permanency planning programs and educating clients, social services providers, and lawyers about the availability and advantages of this new option. Estimates indicate that by the year 2000, more than 125,000 children will be left motherless to AIDS (Geballe, 1995). Standby guardianship provides one mechanism for protecting these children and increasing their chances of growing up in a stable, nurturing environment.

* The feminine form is used throughout this article because of the impact that HIV has on single mothers. Standby guardianship provisions are equally applicable to men and to two-parent families affected by HIV.

— Cynthia Beatty & Bruce Hershfield

Child Welfare League of America

REFERENCES


Since 1989, Lorie Wiener, PhD and Susan Taylor-Brown, PhD have been making videotapes of HIV-infected parents for their surviving children. As parents deal with the painful possibility of dying before their children reach adulthood, many parents fear that their children will forget what they looked like. Videotapes help parents express their love for their children, share their dreams and hopes for their children's future, and leave a visual legacy for them. Each parent decides the content of the videotape, which typically lasts 10 to 20 minutes. Although the process is emotionally challenging, parents describe it as a rewarding experience because it lets them tell their stories in their own words. Drs. Wiener and Taylor-Brown have written several articles on this process, and are developing a videotape, *If Only I Had Asked*. This tape, which will describe how to make legacy videotapes, will include actual videos, along with testimony from parents who have made them.

The Early Permanency Planning Program (EPP) at the Society for Seamen's Children, in Staten Island, NY, has begun to incorporate the use of Lifebooks into work with families whose primary caretaker is dying of AIDS or another terminal illness. Lifebooks are sometimes used with children in foster care to provide a place for them to record their memories and milestones, document their past and explore their feelings. The Society recently developed and produced blank lifebooks, each of which includes a carrying case, a binder with 200 pages (e.g., *The Story of My Birth, Special Events in My Life, People in My Life Important to Me, Things That Make Me Sad*), and crayons, markers, scissors and other materials. Every child in the EPP program is given his or her own Lifebook to complete with the assistance of birth parents, social workers and/or resource parents. The process of developing the Lifebook gives dying parents an opportunity to pass onto their children special memories, thoughts, and information their children can keep with them. It gives children a feeling of self-worth through frequent recognition of even small achievements and life events; memories of who loved and cared for them; and a place for them to process their grief and loss. Children can take the books with them as they move to new homes, so they have lasting memories of their past, and always feel that they were important enough to be photographed and chronicled. Lifebooks also give new caregivers a personal and detailed history of the child's life during the time the child was not in their home. Finally, by working on the Lifebook with children, social workers and parents may learn more about the children, gain insight into their state of mind, better assess their needs, and help them work through their loss.

For a complete description of the videotaping process, see Taylor-Brown & Wiener (1994) "Making videotapes of HIV-infected women for their children," Families in Society, 74(8), 468-480. For additional information on the videotapes, contact Dr. Susan Taylor-Brown at (716) 248-9284, School of Social Work, 313 Sims Hall, Syracuse University, Syracuse, NY 13244, e-mail: Sibrown@syr.edu.

For more information on creating Life Books, contact Susan Maher or Elizabeth Parks at (718) 447-7740, The Society for Seamen's Children, 25 Hyatt Street, 5th Floor, Staten Island, NY 10301.
Joint Guardianship: An Effective Alternative for HIV Infected Families

All family members confronting AIDS are faced with the need to formulate a legally enforceable plan for the future care of the surviving children. As noted throughout this issue, various mechanisms have developed in different states to make this a reality. In California, "joint guardianship" has proven to be an effective tool for helping terminally ill parents plan for the future care of their children.

Enacted in 1994, California’s joint guardianship law allows a custodial parent who is terminally ill to nominate one or more persons to share in the custody of her children (Probate Code s. 2105(f)). Unlike an adoption or conventional guardianship, joint guardianship permits a parent to formally involve another person in the care of her children without completely relinquishing her own custodial rights. California’s statute provides for equal sharing of custodial rights and responsibilities until the death or resignation of one of the joint guardians, at which point custody continues in the remaining joint guardian. In this regard, joint guardianship is unlike standby guardianship, which provides for a complete transfer of custody upon the parent’s death or incapacitation. With joint guardianship, if the noncustodial parent of a child objects to the proposed plan, the court must find that his or her custody would be detrimental to the child before ordering the proposed joint guardianship. If there is no objection from the noncustodial parent, the court need only find that the proposed joint guardianship plan is “necessary and convenient.” (See Probate Code s.1514, Family Code s.3040, 3041.)

This article reports the experience with joint guardianship at the HOPE Project*, and the benefits and disadvantages observed to date. With the proper foundation, joint guardianship can help minimize the disruption in a child’s life during a parent’s illness and following a parent’s death.

Discussion

The shared custody aspect of joint guardianship makes it particularly well suited to HIV affected families. In its later stages, AIDS often results in periods of incapacitation so that a parent may be ill enough to require hospitalization at one point, yet well enough to resume care of her children shortly thereafter. Joint guardianship enables the joint guardian to take whatever steps may be necessary to care for the children during the parent’s hospitalization; it also, however, leaves the parent in a position to resume care of her children upon her release from the hospital. Unlike stand-by guardianship, in joint guardianship both parent and joint guardian are legally and psychologically positioned to care for the children until the parent’s death. This helps to avoid disputes over the parent’s incapacitation and the need to identify a point at which custody is transferred. Because parent and joint guardian share custody equally from the time of the court’s order, however, both must work together to resolve any disputes that might arise concerning the care of the children. Problems can be avoided by encouraging parents to choose a guardian with whom they feel comfortable and can maintain a working relationship. In successful joint guardianships, parents have typically nominated relatives, close friends, or others already involved in the family’s daily life.

Another significant benefit of shared custody is the development of a working relationship between the non-parent joint guardian and the family before the parent’s death or incapacitation. If guardianship proceedings are started early enough in a parent’s illness, the parent not only has time to impart her wishes for the future of her children, but is also able to rely upon the guardian to share responsibility for raising the children as she deals with her illness. For the guardian, it offers the opportunity to develop a close relationship with the family while beginning to share the responsibility of caring for their children. The children, too, benefit from this arrangement, as they have the time to develop a close relationship with the guardian without disrupting their family ties. This assures that, upon the death of the parent, the guardian is truly positioned to provide consistency of care for the children.

Joint guardianship also offers the terminally ill parent a tangible means of managing the impact of AIDS on the family. When joint guardianship proceedings begin early enough in the parent’s disease process, the parent is able to “settle matters” before becoming incapacitated by illness. The act of petitioning for joint guardianship sets a time and place for any objection to the terminally ill parent’s plans while the parent is still able to effectively voice her wishes for her children. Though sometimes difficult, the completed joint guardianship is usually a relief for the entire family.

1 The statute currently defines a terminal condition as one that “will, within reasonable medical judgment, result in death within two years.” A bill amending the statute to remove this “sick enough” clause was signed by Governor Wilson on August 2, and will be law as of January 1, 1996.

Please see next page...
Special Considerations

Families living with HIV face a unique set of psychosocial issues that potentially hinder their ability to participate in effective permanency planning for their children. Legal and social service providers must be prepared to invest a significant amount of time in order to lay the groundwork for a successful guardianship. Providers should proceed with a nonjudgmental approach aimed at demystifying the legal process while acknowledging the complex issues faced by these families. If one does not have a trustful relationship established with the client, it is essential to work with a community provider that does. Attorneys and caseworkers must be respectful of the enormous courage it takes for a parent to plan a part of their children’s upbringing that they are likely to miss.

As HIV increasingly becomes a disease of the economically disadvantaged, it is also important that providers take into account the effects of poverty on the way a family handles an HIV diagnosis. Families understandably must receive services that address their basic survival needs before they can undertake the emotional task of planning for the future of their children. Additionally, it is vital that care providers strive to be culturally sensitive and aware of the impact that AIDS is making on particular communities. Every effort should be made to understand the cultural influences in a parent’s decisions regarding her children.

Finally, providers must acknowledge the stigma surrounding an AIDS diagnosis and the fact that this may result in denial or a desire for secrecy on the part of some families. To some extent, denial may be useful as it protects the client from information that might be too much to handle all at once. Joint guardianship again fits this aspect of the disease, as it allows a parent to enlist the support of someone to help care for her children without relinquishing her role as parent. Providers should work with clients at their own pace, keeping in mind the complex process of accepting a terminal illness and the additional complications of living with AIDS.

Future Implications

While many HIV-infected parents have extended family members and close friends who are obvious and natural choices for joint guardians, there are many who do not. More must be done to link those families without support to the networks of families considering adoption of HIV-affected children. Joint guardianship could be useful in establishing this connection by providing the prospective adoptive family with some assurance of a role in the child’s life without threatening the parent’s custody rights. Adoption is rejected by many terminally ill parents not because they do not want permanency for their children, but because they simply do not want their parental rights terminated before their death.

As more states across the country address the need to provide HIV-infected parents with a means of planning for the future care of their children, joint guardianship should be considered as a viable option. As with any successful permanency planning, joint guardianship avoids the needless placement of children in foster care and the resulting financial and social costs. Beyond that, however, it enables the family itself to identify those sources of support which will minimize the disruption in a child’s life following her or his parent’s death. In this respect, joint guardianship is a tool that effectively implements the underlying rationale of permanency planning and family preservation.

* The HOPE Project at Legal Services for Children provides legal and social services to low-income, HIV-infected families living in San Francisco. Specifically, the project offers assistance in planning for the future care of HIV-affected children, case management, a support group for HIV-affected family members, and a summer family activities program. The Project currently has a caseload of 40 families and has completed over 20 joint guardianships.

— Jean Lewis, JD, HOPE Project Attorney
— Marybeth Kent, EdM, Social Services Coordinator, HOPE Project

Call For Articles

The AIA Resource Center (AIARC) is soliciting articles for the Spring 1996 issue of The Source, which will focus on family planning with women affected by substance abuse. The AIARC invites individuals to submit articles that describe effective practices, innovative programs or current policy in this area. Specifically, the AIARC is looking for articles that address: (1) effective strategies for incorporating family planning services into general social service programs for families affected by substance abuse; (2) training to prepare child welfare workers, substance abuse counselors and social workers for working with clients on issues related to family planning and contraception; (3) innovative approaches to coordinating substance abuse, child welfare and family support services with reproductive/gynecological health services; and (4) ethical and legal issues related to counseling on contraception and family planning.

As always, an AIAR program will also be featured in this issue. Staff from any AIAR program which provides family planning services is encouraged to submit a proposal. Articles should describe the AIAR program and its activities related to the family planning theme.

To be considered for publication in this issue, please send/fax a brief (150-200 words) abstract of your proposed article to the AIAR Resource Center no later than Friday, November 10, 1995. Authors of accepted articles will be notified within two weeks of the deadline. Final manuscripts should be between 1,000 and 2,500 words, and are due January 12, 1996.

Send/Fax abstracts to:
Amy Price
National AIAR Resource Center
1950 Addison Street, Suite 104, Berkeley, CA 94704-1182
Fax: 510-643-7019 • Phone: 510-643-8383
of the staff and the foster/adoptive families is also imperative.

Recruiters should also realize that, while there are many people who express interest in working with the families affected by HIV, very few typically follow through. FCS' experience suggests that, on average, one-out-of-fifty inquiring individuals will immediately become a foster/adoptive family. Many people will contemplate becoming a foster/adoptive parent for a year or more before taking any further steps.

Although recruitment is important, it should be noted that it is not necessary to spend a lot of money on recruitment activities. FCS has had great success on a small budget. The most effective efforts have involved use of local TV and radio stations to play public service announcements (PSAs), as well as sending out press releases to all community newspaper and TV stations. FCS has used a participating family and their adoptive children to help promote the program and educate the community on HIV. In addition, FCS staff speak to those who have a special interest in HIV, e.g., members of some churches, professional and volunteer organizations, as well as staff from local hospitals and departments of social services throughout our region.

FCS currently has the following standards for foster/adoptive parents:

- Income over $12,000 per year;
- 25-55 years of age;
- Willingness to work with biological families;
- Willingness to work with those infected with HIV;
- Single parents or couples; and
- Working or unemployed/retired families.

Prospective foster/adoptive parents must go through a home study process and attend 24 hours of pre-service training. This training addresses:

- How to work with biological families;
- How to care for a child with HIV infection;
- Child development and discipline;
- Issues of separation, grief and loss; and
- Differences between foster care and adoption.

Outcomes

FCS began its HIV-focused treatment foster care program in July 1994. Through June 1995, the project has served 33 children. Of those, three were reunified after an average of five months in care. FCS has placed six with relative resources for periods of time ranging from three days to two years. Four foster/adoptive parent adoptions have been completed and two more are in progress. Of the additional eighteen children in the program, 50% have been in care for less than eight months and permanency planning is progressing. FCS has had approximately 300 inquiries from prospective foster/adoptive parents, and has approved seven foster/adoptive homes. Eleven more are in study. Overall, FCS has found that permanency for children impacted by HIV can be ensured through flexible, intensive service delivery to them, their birth families and their foster/adoptive families.

- Melissa Byars, LGSW, Adoption Specialist, Family and Children Services
- Angela S. Rave, FaCT Model Project Coordinator

* The FaCT Model Project (A Family-Centered, Community-Based Transagency Model for Children Affected by HIV Infection, AIDS or Substance Abuse) with the Social Services Administration, Maryland Department of Human Resources, is an Abandoned Infants Assistance (AIA) project within the state child welfare system. Case managers, both within local departments of social services and within FCS, the private agency partner, provide services to families affected by HIV, AIDS or substance abuse.

** FCS defines a child as being impacted by HIV if he/she is testing HIV+, has tested HIV+ in the past, or if his/her parents are HIV+ or have AIDS.

BUILDING BRIDGES

Building Bridges is a new collaborative project involving a national working network of advocates, providers and families who are involved in planning for the future care of children who have or will become parentless due to HIV/AIDS. The project's goal is to increase the availability of different options which facilitate early planning for HIV-infected parents, and raise awareness of the needs of these families. It intends to accomplish this by pulling people together to:

1. Share experiences, information and program models;
2. Support legislation which makes more options available; and
3. Collaborate on manuals and trainings for advocates, providers, parents and guardians. The project is seeking input, participation and support to build these bridges and ensure that families can place their children in safe, supportive and stable homes.

If you are interested in participating, or would like additional information, please contact:

Kristin Neil
c/o National Women & HIV/AIDS Project
710 Eye Street, S.E.,
Washington, D.C. 20003
(202) 547-1155

REFERENCES


As these questions demonstrate, many factors affect a plan's viability, and conflicts can arise between clients and professionals and among team members about a client's choices (Herb, 1995). Professionals have to ask themselves: Who is my client? Only the parent? If so, who represents the children? Can the family be my client? Are there some custody plans I cannot in good conscience take legal or agency steps to implement? Should I then withdraw from the case or refer the client to someone who will accept the plan? What if there are no good alternatives?

The process of resolving these dilemmas will be as challenging to professionals as is the process of constructing a viable custody plan to clients.

— Carol Levine, MA, Executive Director, The Orphan Project, New York City
— Barbara Draimin, DSW, Director, The Family Center/MHRA, New York City
— Laurie Bauman, PhD, Co-Director for Research and Evaluation of the Preventive Intervention Research Center for Child Health, Albert Einstein College of Medicine, The Bronx, New York

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