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IN THIS ISSUE

- 1 Legal Permanency Planning for HIV-Affected Families: The Need to Plan, Current Legal Options, and Future Directions
- 7 Creating a Secure Future for Children Whose Parents Have a Life Threatening Illness
- 13 What are Standby Guardian Laws?
- 15 Challenges and Opportunities in the Sociolegal Relationship in Permanency Planning with HIV-Positive Parents
- 20 Effective Practices for Empowering Parents with HIV/AIDS Through Peer Support
- 23 Disclosure: The Challenges and Benefits for Children Affected by HIV
- 26 Good Bets
- 29 Conference Listings

LEGAL PERMANENCY PLANNING FOR HIV-AFFECTED FAMILIES: THE NEED TO PLAN, CURRENT LEGAL OPTIONS, AND FUTURE DIRECTION

The number of families affected by HIV in the United States has grown exponentially over the years. According to the U.S. Centers for Disease Control (CDC), between 120,000 and 160,000 adult and adolescent females are living with HIV or AIDS (CDC, 1999). The proportion of AIDS cases among adult and adolescent women more than tripled, from 7 percent in 1985 to 23 percent in 1998. Women represent an estimated 30 percent of the 40,000 new HIV infections each year (CDC, 1999). AIDS is now the second leading cause of death among African American women ages 25–44 (CDC, 1999).

The epidemic's impact on children who are or may be orphaned by the disease has also increased exponentially. In 1994, an estimated 7,300 children and adolescents were orphaned by HIV/AIDS. By this year, 2000, it is conservatively projected that the overall number of motherless children and adolescents will exceed 80,000, and this number may reach 125,000 (Levine and Stein, 1994).

Parents with HIV/AIDS face extraordinary burdens and challenges when planning for future care and custody of a child. Legal and psychosocial issues that HIV-affected families face

when arranging for a future caregiving situation can include:

- disclosing the parent's illness, which may pose a threat to family and other relationships, employment, religious and community status, and personal safety;
- facing the prospect of a legal dispute with the child's other parent or another person with legal standing;
- dealing with substance abuse and mental health problems;
- addressing current or past child welfare system involvement;
- overcoming mistrust of the legal system;
- securing a legal plan that is responsive to the child's and family's needs for permanency and supportive benefits;
- accepting the reality of the disease; and
- identifying a willing and able substitute caregiver.

While most parents have thought about what would happen to their children in the event that they are unable to care for them, few have taken the steps necessary to make a legal permanency plan. Many mothers find it too painful to discuss the need for permanency plans

Continued on page 2 . . .

Continued from page 1 . . .

with their children and potential caregivers. Many also do not know how to make a legal plan, and most lack the legal and other supportive resources to do so (LSC and Associates, 1998).

Even when legal resources are available, some families may find it difficult or even impossible to make a legal permanency plan. If the child is in foster care, the family's ability to participate in a legal permanency plan may be frustrated by short permanency timelines imposed by the Adoption and Safe Families Act (ASFA). If the family has the legal authority to make a plan, they may have trouble reaching agreement about the best plan of care. In some families, no legally qualified caregiver is available. In others, the parent may have no one to whom the future care of the child can be entrusted.

Yet achieving a legal permanency plan for a child who may be orphaned can be critical to the child's safety and well being. Without a legal permanency plan, a child may be at risk of abandonment or foster care. Supportive legal and social work services can help prevent disruption of birth families before legal plans are made and implemented, and can help new caregiving families during and after the child's transition.

Both conventional and newer, more innovative legal mechanisms can assist families who wish to make voluntary legal permanency plans. This article will present the current voluntary legal planning options available to families. It will also discuss ASFA's effect on permanency planning. Finally, some suggestions for the future will be offered.



Voluntary Legal Permanency Options

The concept of voluntary legal permanency planning—that parents have the

right to make legal permanency plans in the best interest of their children—is a relatively old notion based on the law of property and estates. Historically, making a legal plan for a child was done in conjunction with planning for the post-death disposition of property. However, traditional legal methods of voluntary permanency planning have not met the needs of parents with HIV who are concerned about living with the disease, keeping their children with them for as long as possible, and making practical and legal permanency plans for their children's future.

Conventional legal planning mechanisms available to parents in virtually every state include testamentary and inter vivos guardianships (see below). More recent, innovative mechanisms have been developed in large part as a response to the needs of HIV-affected families. Parents with HIV, often in crisis when they seek legal assistance, live in situations that require more flexible and responsive legal planning not previously available through traditional legal planning options. For example, most parents wish to keep their children in their care for as long as possible. Yet they also wish to ensure that their permanency plans for the future will be legally valid. Recent reforms in voluntary legal permanency planning have included standby guardianship, joint and co-guardianships, short-term guardianship and other private designations including delegated caregiver authorizations, and standby adoption (Selbin and McAllaster, 2000).

All of the legal mechanisms described in this article are tools that may help families make and carry out their own permanency plans. The choice of a family's permanency plan must be made within the context of the particular family's situation. This includes the family's legal needs and issues, as well as other issues that may be present, such as psychosocial needs and concerns about the child's best interest.



Conventional Legal Planning Mechanisms

Testamentary guardianship is a guardianship preference stated in a will or other legal writing that takes effect after the parent's death, following court approval. Testamentary guardianship is initiated when a parent nominates a guardian in a will (or other writing that is legally enforceable). Through the will or other writing, a parent can express preferences regarding a future guardian for the child. However, initiation of a future guardianship through a will does not, in and of itself, ensure that a court will appoint the person nominated by the parent as guardian of the child. Though courts generally give preference to a parent's wishes, guardianship nomination is not legally dispositive; that is, the court is not bound by the parent's preference. Guardianship nominations can be contested by another person with legal standing, and the court could find that the parent's choice of guardian is no longer in the child's best interest. If the child has another legal parent, the court may not appoint another person to be the child's guardian unless the legal rights of the other parent have been terminated, or the other parent agrees to the guardianship.

Another disadvantage to testamentary guardianship is that it is not probated until after the parent's death. Thus the parent is not available to give what could be, in contested matters, key testimony as to her or his preference concerning the guardianship nomination and the child's best interest.

Further, testamentary guardianships are not of assistance in situations in which a parent becomes incapacitated (even temporarily) and is in need of the proposed guardian's help to provide direct care for a child. It is important to remember, however, that a will, which may also include a testamentary

guardianship, is a significant component of a comprehensive legal permanency plan.

Inter vivos guardianship is a complete and immediate transfer of guardianship from a parent to another qualified adult during the parent's lifetime. A traditional *inter vivos* guardianship transfers day-to-day care and control of the child, and many other decision-making rights (including health care and educational decisions). After going through a court process in which a petition is filed (usually, but not always, by the parent) and notice is provided to persons legally entitled, a best interests hearing is held by the court. If the court gives its approval, the guardian assumes immediate responsibility for the child. Therefore, *inter vivos* guardianship is not useful to the parent who still wishes to keep the child at home for as long as possible. However, *inter vivos* guardianship can be advantageous to a family in which a terminally ill parent is ready to transfer guardianship (for example, to a parent who is living with the proposed guardian and is unable to provide day-to-day care for the child).



Recent Reforms in Voluntary Legal Permanency Planning

Standby guardianship is a mechanism for ensuring legal permanency for a child that is contingent on the occurrence of a future event—usually the death or incapacity of the parent. In essence, the standby guardian literally “stands by” until needed, and assumes responsibility for the child once the “standby” duties are activated.

As of July, 2000, standby guardianship had been enacted in at least 20 states (see Larsen article in this issue). Although states have taken the lead in developing standby guardianship statutes, as part of the 1997 federal

Continued on page 4 . . .

STANDBY GUARDIANSHIP: ESTABLISHING PERMANENT FUTURES FOR CHILDREN

The National Abandoned Infants Assistance Resource Center provides information, training and technical assistance on standby guardianship.

Services are available, at no cost, to assist with developing legislation for standby guardianship. Information and referral services are available to social service organizations, legal service providers, and policy makers. On-site training and technical assistance are available to select states and regions.

Training and Technical Assistance

- Consultation on the legal, psychological and social aspects of standby guardianship.
- Contract with nationally recognized experts to provide local consultation and training.
- Facilitate local conferences and meetings.
- Develop and/or provide referral to informational and educational resources.
- Provide assistance with research and analysis of local issues and concerns.

Research and Information

- Standby guardianship fact sheet.
- Database of experts in the field.
- Review of legal, psychological and social service literature.
- Analysis of existing and emerging legislation throughout the United States.
- Informational web site:
<http://socrates.berkeley.edu/~aiarc>.



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Continued from page 3 . . .

Adoption and Safe Families Act (ASFA), a “Sense of Congress Regarding Standby Guardianship” was adopted which encourages states to enact standby guardianship laws and procedures (ASFA, Section 403). In 1998, the American Bar Association (ABA) also acted to encourage uniform establishment of standby guardianship (Uniform Guardianship and Protective Proceedings Act (1998), Section 5-502).

While no two state standby guardianship statutes are exactly alike, some common elements of most (but not all) state standby guardianship statutes have been identified. These include:

■ *Designation of a standby guardian.*

Most states provide a process for a legal writing, similar to a will, for designating a person to be the standby guardian. Unfortunately, most (but not all) states also make this designation contingent on the parent’s having “terminal” or “chronic” illness. (However, Connecticut, Florida, Illinois, Iowa, Massachusetts, Pennsylvania, and Wyoming do not limit the use of standby guardianship to a particular health status.) The standby guardianship becomes activated upon the occurrence of a “triggering” event, usually the death or incapacity of the parent.

■ *Agreement of non-custodial parent:*

Non-custodial parents are provided the opportunity to be heard on the issue of guardianship, and “reasonable” or “diligent” efforts must be made to notify the non-custodial parent of the court proceeding.

■ *Role of the standby guardian:* The guardian assumes responsibility when the future event or condition occurs, and must also bring to court evidence that the “triggering event” has occurred. If the standby guardian’s duties are triggered during the parent’s lifetime (for example, while the parent

is incapacitated), the standby generally works in conjunction with the parent’s consent.

- *Court Process:* The court will determine whether a standby guardianship appointment is in the best interest of the child. This determination occurs after the document designating the standby guardian is filed in court. The guardianship can be confirmed only after evidence is brought to the court that the triggering event or condition has occurred. A physician’s statement is required if the triggering event is mental or physical incapacity of the parent. After a parent’s death, a standby guardianship “converts” to a permanent guardianship of the child. This may require an additional court hearing (Larsen, 2000, pp. 8-9).

There are several advantages of standby guardianship vs. conventional planning mechanisms. Transfer of guardianship is not immediate, but occurs only when the standby guardian’s duties are activated. Until that time, the parent retains custody of the child. Standby guardianship also provides the parent with the opportunity to provide testimony regarding the child’s best interests. Standby guardianship can also provide some peace of mind to the parent who knows that the chosen legal plan will take effect when needed.

Standby guardianship has proven to be a useful planning tool for parents who wish to retain custody of their children for as long as possible, yet also want to secure a legal, court-ordered plan for their children. In Illinois, the AIA-funded Family Options Project has provided legal services to secure court-ordered and other legal permanency plans (including guardianships, standby guardianships, and adoptions) for 125 children (see column on p. 12 of this issue). Of these, 39 have standby guardianships in place.

Each state has its own statutory and procedural requirements for standby

guardianship. Service providers assisting HIV-affected families should work with a local attorney to determine the exact provisions of both state standby guardianship law and local procedural requirements.

Variations on the standby guardianship theme—joint and co-guardianships: While most states provide for the appointment of two or more co-guardians of a minor, co-guardianship is typically awarded to one or more persons who are not the parent of the child. Some more recent reforms have been enacted in Connecticut and California that introduce standby guardian elements into more traditional guardianship mechanisms. In both states, a parent may nominate another person(s) to serve in a shared guardianship capacity along with the parent. These joint or co-guardianships can have immediate effect. Connecticut’s statute also provides that the co-guardianship can take effect upon the occurrence of a contingent event, usually the death or mental or physical incapacity of the parent. California’s statute requires that the parent be terminally ill in order to nominate a joint guardian; Connecticut’s does not contain a health status restriction. In California, the joint guardianship authority is shared between the terminally ill parent and other joint guardians. In Connecticut, the co-guardians may act independently (Selbin and McAllaster, 2000).

Short-Term Guardianship and Other Private Designations: During the course of developing a permanency plan, a family may wish to delegate decision-making authority on a temporary basis to another adult. This delegation of decision-making authority can be especially helpful when a parent is temporarily incapacitated due to illness and/or hospitalization.

Illinois’ short-term guardianship law was developed to respond to the needs of HIV affected parents, but can

be used by any parent regardless of health status. A short-term guardianship is a guardianship created by private agreement between the parent and another qualified adult. The agreement may convey guardianship responsibility for a period of up to 60 days. A statutory form is provided in which the parent can indicate when the short-term guardian's authority will commence (either immediately or upon a specific event or future date). The short-term guardian has all of the authority to act as guardian of the minor's person, and also has the authority to apply for and receive benefits on behalf of the minor. Short-term guardianships are renewable. Two witnesses must sign the appointment. The child's other parent may also join in the appointment, but the other parent's consent is not necessary if the other parent has died; the other parent's whereabouts are unknown; the other parent is not able to make and carry out day-to-day child care decisions; or legal parentage was never established. A short-term guardian may be appointed by either the child's parent or the child's guardian (755 ILCS 5/11).

The District of Columbia's Authorization for Medical Consent for a Minor by an Adult Caregiver permits a parent, guardian, or legal custodian to authorize another adult who is providing care for a child to consent to the child's medical and dental care. This authorization is intended to be temporary, but the statute does not limit the duration. (D.C. Code Ann. § 16-4901.)

Other examples of private designations of decision-making authority include: California's "Caregiver's Authorization Affidavit" (applicable to both relative and non-relative caregivers) (Cal. Fam. Code § 6550); Delaware's "Affidavit of Establishment of Power to Relative Caregivers to Consent to Medical Treatment" (Del. Code Ann. tit. 13, §§ 707-708); Louisiana's "Provisional Custody by Mandate" (La. Rev. Stat.

Ann. §§ 9:951-954); Minnesota's "Designated Caregiver Agreement" (Minn. Stat. Ann. § 257A.01); and North Carolina's "Authorization to Consent to Health Care for Minor" (N.C. Gen. Stat. §§ 32A-28-34) (Selbin and McAllaster, 2000).



When a Family Lacks the Authority to Make its Own Plan: Some Observations Concerning ASFA's Effect on Permanency Planning

The legal permanency planning options discussed above are ones that can be used by HIV-affected families on a voluntary basis. That is, a family can, at its own option, make and carry out its own plan for legal permanency for the child. However, some families lack the ability to make their own permanency plans, particularly those in which the child is in the custody of the state or county child welfare system.

In its attempt to secure safety, more timely permanency, and increased rates of permanency for children, the Adoption and Safe Families Act (ASFA) also created timeline requirements that are aimed at termination of parental rights and traditional adoption. A problem experienced in many states is the conflict between the amount of time needed to effectively resolve the birth family's issues (for example, mental health and substance abuse problems) and ASFA's short permanency timelines (Matthews and Cheng, 2000, pp. 3-4). This conflict is even more problematic where adequate services are not available to address the problems that put the child at risk.

For families with HIV, this conflict raises additional issues. Parents whose children are in child welfare custody and out-of-home placement face the possibility that the child will not be reunified

with the family, that termination of their rights followed by adoption may occur, and that their relationship with their child could legally end. The termination process itself can also preclude any direct permanency planning efforts on the part of parents, and their ability to ever participate in permanency planning will ultimately be curtailed once termination occurs. HIV infected parents are frequently impacted by multiple issues including: accessing and managing medical care; dealing with substance abuse treatment and relapse; addressing issues of discrimination (for example employment, education, housing, insurance); and psychosocial issues related to their illness and the stigma and isolation of HIV. Improvements to the ASFA requirements could include recognition that families in different situations with varying constraints have different ways of achieving permanency, and that timelines, services, and legal options should be designed to provide a balance that recognizes the family's need to correct conditions that put the child at risk, and the child's need for permanency.

In cases in which parental rights are likely to be terminated, potential methods of impacting permanency are limited and depend to a large extent on the willingness of the local child welfare system to work with the family's situation. In many states, subsidized guardianship and adoption assistance programs can make it possible for relatives (or other caregivers chosen as part of a family's permanency plan) who meet state requirements to become private guardians or adopt with financial and medical assistance. However, the extent to which programs of subsidized guardianship or adoption assistance can be effective is contingent upon the adequacy of information and counseling, including legal advice, provided to potential relative or "kinship caregivers."

Further, the long term consequences of adoption or guardianship by relatives

Continued on page 6 . . .

Continued from page 5 . . .

who, without available financial assistance would not legally take on parental status, is not known. As children in kinship adoptions reach adolescence, adoption disruptions may increase. The ability of older caregivers, in particular, to provide care may be impacted by illness or the caregiver's death.

For those families with HIV who do not have even the limited possibility of participating in permanency planning through a relative or other chosen caregiver, the requirements of ASFA may preclude resolution of unsettled birth family relationships prior to the parent's death. For these reasons, it is clear that public child welfare systems must improve their response to families with terminally ill parents.



Future Directions

Voluntary legal permanency planning reforms developed since 1990 have greatly increased the number of options for families affected by HIV. More flexible legal alternatives are now in place in many states, and more states are working toward passing standby guardianship and other reforms.

The newest legal option to be established is standby adoption, which became effective in Illinois law on January 1, 2000 (750 Ill. Comp. Stat. 50/5-18). Standby adoption evolved in response to the needs of clients in the AIA-funded Family Options Project in Chicago. The Project provides legal and social work services to HIV-affected families who wish to make permanency plans (see column on p. 12).

Standby adoption was developed in order to provide a more flexible adoption alternative for families when birth parents are terminally ill. While a traditional adoption offers the most permanency for a child, few families receiving Family Options Project legal services

choose adoption as a planning mechanism, since it requires termination of parental rights and relinquishment of care and custody.

Standby adoption provides for an appointment of a person who will adopt the child of a terminally ill parent on a specified event, either the death of the parent or the parent's request to the court that the adoption should be finalized. The standby adoption process includes all of the requirements of a regular adoption process, except the adoption is not finalized until a later date. The parent also executes a specific consent for standby adoption, so that only the individual(s) chosen by the parent may adopt the child at the parent's death or desire to complete the adoption. If, at the parent's death, the standby adoptive parent does not move to finalize the adoption, the adoption will not be finalized.

Standby adoption has advantages that parallel those of standby guardianship. First, the parent is present and able to provide testimony concerning the child's best interests. Second, transfer of care and custody is not immediate, and the parent can continue to provide care and retain custody of the child for as long as the parent wishes. Third, standby adoption can provide the birth and adoptive family with peace of mind concerning the legal permanency status of the child. Finally, standby adoption offers more security for permanency than do other available planning alternatives.

Even with the progress made to date in legal permanency planning options, there are still other areas of policy and law that merit exploration. These include:

- Child welfare policy improvements that recognize that families in different situations with varying constraints, including HIV/AIDS, need more flexible standards for achieving permanency and/or maintaining relationships with children who may be orphaned;
- Permanency planning initiatives for older caregivers, including those who

adopt or become private guardians of children through the child welfare system, so that successor plans can be made in advance of death or incapacity; and

- Legal options that promote permanency by allowing relative caregivers to assume legal responsibility for children and receive financial support without having to sever ties to birth parents.

Needed improvements in these areas could help both HIV-affected families and other families concerned with making permanency plans for their children. It is likely that, in the future, more flexible laws and policies that impact families at risk will continue to be initiated or at least influenced by the movement to expand the legal options for families with HIV.

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CREATING A SECURE FUTURE FOR CHILDREN WHOSE PARENTS HAVE A LIFE THREATENING ILLNESS

Founded in 1994, The Family Center was created to address the substantial increase in the number of children in New York City who were being orphaned as a result of parental AIDS and other illnesses. Many parents with AIDS were not making future plans for their children, and often when plans were made they were done in the last stages of illness when families were in crisis. It was not unusual for decisions about who would care for the children to be made at the funeral. The resulting plans were often vulnerable, resulting in children moving from one caregiver to another after the death. These unstable plans put children at increased risk and highlighted the need for services to assist parents to create better plans with more secure outcomes.

The Family Center's founders recognized that the most secure permanency plans for these children addressed the legal, psycho-social support and entitlement components of planning in a coordinated fashion. As a result, the Center was founded as an independent organization whose mission is to assure a secure future for children whose parents have a life threatening illness by providing a mix of these services. Over the last six years, services have evolved that stabilize families before and after the parent's death. Particular attention has been given to addressing mental health problems, ongoing substance use, and multi-generational parenting needs in these families.

The following overview of The

Family Center's services illustrates the complexity of providing permanency planning services for families and highlights three key elements of our strategic approach to our mission. First, the services are family-centered, striving to involve all persons integral to the plan as early as possible. Second, a coordinated multi-disciplinary team approach is employed to provide the services most suitable to each family's needs. Third, The Family Center is committed to providing continuity of services to families, working with the parent and nominated caregiver to develop a viable plan before the death and assisting the new caregiver with implementing the plan after the death. These three aspects of our work — family-centered care, multi-disciplinary team approach, and continuity of services — are instrumental to our success in helping families. They form the basis of how we operate and how we train professionals in other locations to adopt The Family Center's permanency planning model.



Background

Parents with life threatening illnesses are haunted by one troubling question: "What will happen to my children when I die?" It is not only parents who have fears about the future. Their children are also affected, wondering how their lives might change and fearing for the loss of

their sense of family. Other family members also fear changes in their relationship with the children. Future or potential caregivers have concerns about their suitability to assume the responsibilities and the burden that this will place on their current family structure.

For parents, the emotional challenge of confronting the reality of one's imminent death is further complicated by the sadness of the anticipated loss of seeing their child grow and develop. Reluctance and confusion about the future, compounded by the pressing needs of a critical health problem, frequently lead to postponement of permanency planning. Emotional challenges faced by the family during this process may be further complicated by ongoing mental health and substance use issues and problems in family functioning.

The first step to effective permanency planning requires that the parent recognize the importance and urgency of making a plan for their children's future. With that focus, the parent then can assess issues of personal importance that are relevant to choosing a person to care for their children. Decisions about the characteristics most important in a caregiver are made in the context of the parent's personal goals for the children's future. These may include consideration of issues such as their preferences for the child's religious upbringing and educational experience as well as their beliefs about how the child should be raised and

Continued on page 8 . . .

Continued from page 7 . . .

disciplined. Careful consideration as to the best placement of each child must also be given to all siblings, particularly when the non-custodial parents of the children are different. The financial ability of the desired caregiver or caregivers to support the child or children must also be considered at this step.

Once the intended caregiver is identified, the parent needs to decide how and when she wishes to communicate her desired plan to the proposed caregiver. This step frequently includes the often difficult decision to disclose the nature and immediacy of the health condition, so that the intended caregiver can be prepared to assume responsibility and can assist in the transition (see Murphy article on p. 23 of this issue). At this point in the planning process, the parent will also consider the benefits and challenges of speaking with the child about the plan, taking into consideration the child's age, the timing of the conversation, the child's knowledge about the parent's illness, and other factors that will affect the child's understanding of and reaction to the knowledge that a plan is being made. Next, the parent determines the best way to document and secure the plan. This step involves consulting an attorney to consider the legal and benefit issues which vary from state to state due to differing statutes and laws.



The Family-Centered Approach

Through a strategic mix of legal, entitlement and psycho-social services, Family Center staff members guide families over the emotional, familial, institutional and legal hurdles they face to assure a secure future for the children. Family Center staff work directly with the parent, always maintaining the focus on what is best for the child. When there are rela-

tives who have an interest in the welfare of the child, Family Center staff help the parent invite them to participate in the process as early as possible. When there is disagreement about what would be best for the child, this encouragement to involve others is sometimes difficult for the parent to accept. However, experience has shown that conflicts left unresolved before the parent's death often result in challenges to the plan once the parent has died.

Ill parents face few decisions more difficult than determining the best plan for the future of their children. Even those committed to securing plans will understandably have periods of ambivalence about moving forward in the planning process. It is common for parents to alternately approach and then avoid this critical task due to the crisis and sadness brought on by their condition. There also are many complexities to permanency planning itself. Given the clear focus of The Family Center's organizational mission and the time sensitive nature of the work, staff must stay on track in order to be successful.



Engaging Clients

Maintaining client engagement is a serious challenge in this work, and one The Family Center addresses both on a programmatic and individual staff level. For instance, staff are trained to be "pleasantly relentless" in pursuit of their objective to assist parents in facing their responsibilities to plan for their children's future. At times when planning is not the family's central priority, staff will seek alternative ways to maintain engagement while working as quickly as possible to re-involve the parent in the planning. Family Center services stress relationship building as key to completing the planning. Adjustments in the pace and content of the work are made as necessary in order to allow parents and other family members the time needed to complete

each step, while retaining the focus on the final goal of having a plan in place for each child.

A parent's first contact with The Family Center is generally a phone conversation with the program supervisor, who conducts a brief assessment and assigns the case to a family specialist. The family specialist's role is to lay the groundwork for the Center's relationship to the parent and his or her family, to coordinate the services the family receives, and to guide the parent to a Family Center attorney who will complete the legal documents necessary to secure the plan.

Unlike most other social services, The Family Center conducts the majority of its work with the family directly in the home. The family specialist visits with the ill parent, assesses the parent's readiness to make a plan, helps to establish the parent's goals for the family, and functions as the case manager or coordinator of services throughout the entire permanency planning process. The family specialist initiates the permanency planning discussion directly in the familiar home setting, creating an intimate and focused discussion in the place where the parent feels most secure and in control. The home visits also provide a more realistic picture of the children's current home environment and usually offer opportunities for the staff to more accurately assess family strengths and weaknesses that may impact the plan. Together, the parent and the family specialist prepare a genogram of the entire family to explore the existing and potential emotional and financial support networks, and to outline possible choices for a future caregiver. The genogram is done with every parent at the first or second visit and is a critical tool in assessing the options and focusing the work. (See sample genogram in case study.)

Family specialists generally make bi-weekly home visits to the families. Given that the needs and interests of the parents vary, they are encouraged to select a starting point for their permanency planning

work from a novel and comprehensive menu of topics, such as “talking to others about your illness,” “permanency planning options,” and meeting with “future caregivers.” The family specialist then guides the parent through the decisions and actions relative to that topic, seeking to identify concerns, resolve problems and foster action. For many parents, their child’s current development, school performance, behavior and adjustment are of primary concern. In these families, the planning work for the future begins with an assessment of how the family is doing in the present. The work may focus on these issues of present concern for some time as families define their goals in these areas.



A Multi-disciplinary Team

The family specialist serves as the coordinator of all the services for the family, frequently bringing in other staff members to assist in selected steps in the permanency planning process or as needed to help resolve specific problems. The Family Center team currently includes: 8 family specialists, 4 attorneys and one paralegal, 4 mental health clinicians, one substance abuse counselor, and one entitlement specialist.

When the parent is ready to outline a custody plan in detail, an attorney joins the family specialist on a home visit and is introduced to the family. The attorney reviews the planning options available in New York State, ensuring the client’s full understanding of all of the legal and benefits issues involved with each option. The Family Center works with the parents to either legalize the plan before their death or to ensure that there will be no barriers to legalizing the plan after the death. In addition to providing legal advice and preparing all required documents, the attorney represents the client in family or surrogates’ court to finalize the plan. The lawyer also assists the par-

ent in preparing medical directives, power of attorney, and temporary care and custody agreements. In cases where clients require legal representation in matters other than custody planning, such as immigration or entitlements, the attorney arranges referrals to outside providers with expertise in these areas.

When psychological problems are recognized by the family specialist, one of the clinical social workers on the team is brought in to assess the situation more thoroughly and to provide direct short-term counseling as needed. When longer-term mental health services are needed, the family specialist and the clinician work together to link the family member with appropriate community services and to follow up to ensure that the services are satisfactory.

Family specialists and clinicians often assist parents with decisions about disclosing the nature and extent of the illness to the children, other family members, and potential caregivers (see Murphy article on p. 23 of this issue). The way a parent deals with disclosing the nature and immediacy of the health problem varies from one case to the next. Experience shows that this important step in the permanency planning process is often the most emotionally wrenching and time consuming. Choosing not to disclose can be a roadblock to approaching the intended caregiver and to finalizing the plan. The response of the intended caregiver and other key family members can also shape the extent of the subsequent services provided and, in some cases, can force the parent to reassess earlier decisions.

If the family specialist identifies a parent or other family member’s alcohol or drug problem as de-stabilizing to the family or a barrier to completing or implementing a plan, the substance use counselor will be called in. For those not in treatment, the substance use counselor will assess barriers to accessing treatment services and will develop a plan with the client to address those barriers in a timely



A family advisory committee member and her family at a Family Center holiday event

manner with the goal of treatment access, engagement and follow-through. For those already in treatment, the substance use specialist can provide additional support for the person to continue with a program. This is often critical during the permanency planning process which can trigger significant emotional and familial stress.

As needed, The Family Center’s entitlement specialist provides information regarding the family’s eligibility for social service entitlements, such as disability or survivor benefits. This staff member also frequently serves as a resource for the parent to advocate for and access necessary benefits for the family.



Continuity of Service

The Family Center’s service begins with the initial contact with the parent and extends through the parent’s death to the secure placement of the children with the caregiver in the new family unit. Experience has shown that the members of the reconfigured family structure often need some of the same services as the family required before the death of the parent. Family Center staff provides services directly to new caregivers, including mental health counseling, referral, entitlement advocacy and legal assistance. The children

Continued on page 11 . . .

CASE SUMMARY



The following case summary illustrates the complexity of the permanency planning process and the nature of the services provided by The Family Center.

When Amanda G. first became a client of The Family Center in 1994, she was 37 years old and had been living with HIV for over 6 years. She had recently been diagnosed with AIDS and had several hospital stays for recurrent medical problems. Originally from Puerto Rico, she made her home in New York City, where she lived with Tomas, her youngest son who was 11 years old. Miguel, 20, and Manolo, 18, her two older sons, visited her frequently but each lived mostly with their girlfriends. Miguel and Manolo's father died of AIDS in 1993 and Tomas' father had been incarcerated since 1989. Tomas' father, Enrique, was legally separated from Amanda approximately four years earlier and had limited contact with her or Tomas. While Amanda's former husband, mother, sister, and two older boys knew that Amanda had AIDS and was seriously ill, Tomas had not yet been told.

Due to her declining health, Amanda was motivated to initiate permanency planning for her youngest son. She was referred to The Family Center by her hospital social worker following a 10 day hospitalization for pneumonia. At her first meeting with the family specialist she stated that her goals were to provide Tomas with appropriate future guidance and support. She also needed help in disclosing to Tomas that she was ill and would likely die. Amanda's greatest concern was that Tomas would follow in the path of his brother Manolo with arrests and incarceration on drug related charges.

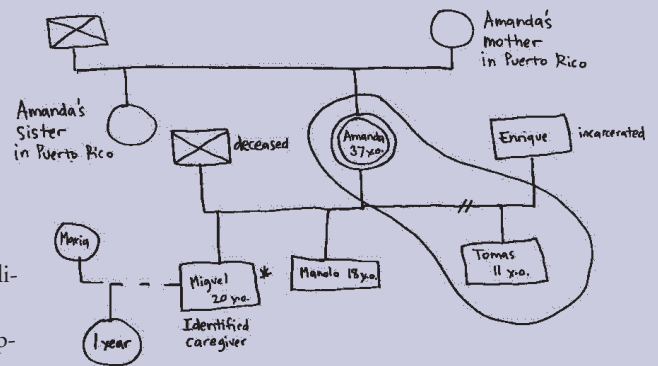
Initially, Amanda identified a few potential options and explored each with the family specialist. She traveled to

Puerto Rico to visit with her mother and sister and considered moving back there with her sons. She spoke with her mother about taking care of Tomas on a long-term basis and even considered housing options in Puerto Rico for her family. Her goal at this point was to have all of her sons move to Puerto Rico, and to have her mother take primary responsibility for Tomas with the two older boys available as backup and support. Amanda's mother felt ill prepared to assume responsibility for an adolescent boy and when Amanda realized that Miguel and Manolo were unwilling to relocate to Puerto Rico, she sought options in New York. Her declining health also motivated her to stay in New York City where her medical care was already established and covered by insurance.

Amanda then identified her son Miguel as a desirable candidate to become Tomas' caregiver. She hoped that he would move back into her apartment and then take care of Tomas there after her death. This plan would allow all the brothers to stay close together and would be the least disruptive for Tomas. Amanda recognized that Tomas was increasingly burdened by her illness and reported that he had turbulent sleep patterns and problems concentrating at school.

As Amanda's health continued to decline, the family specialist suggested involving a Family Center clinician to work with Amanda on disclosure to Tomas and to work with the entire family on anticipatory grief issues and plans for the future. At this point in the planning, Miguel was uncertain about his own suitability to be a guardian for Tomas. His former girlfriend and their daughter lived close by and Miguel was already involved in her upbringing. In addition, his employment history was sketchy and he was considering a move out of state.

Amanda G.'s Genogram



Eventually, Miguel decided to accept the responsibility of his brother's care and, with the help of a Family Center attorney, he became Tomas' court-approved standby guardian in 1997. As Amanda's health continued to deteriorate, Miguel spent more time with Tomas, took on more parenting responsibility and eventually moved into the apartment with his mother and brother.

Amanda died in late 1998. Two months following her death, Miguel went back to court with The Family Center attorney and was granted full legal guardianship of his brother. With the help of the family specialist and clinician, Miguel sought assistance in dealing with Tomas' school performance and accessed continued bereavement counseling. At the time of Amanda's death, Miguel also received assistance in accessing survivor's benefits for his brother.

The working relationship between Amanda's family and the staff at The Family Center was the basis for this successful outcome in planning for Tomas' future. The coordinated delivery of legal and social services, focused on the design and implementation of a legalized permanency plan, resulted in Amanda's wishes being carried out and the smoothest transition possible for Tomas. Family Center staff stay in touch with Tomas and Miguel who report that the last two years have been challenging but they are together and doing well.

Continued from page 9 . . .

are also supported in their adjustment, with mental health counseling, counseling for their grief and loss, and some group support services designed to normalize their experience and help in the adjustment. In cases where questions arise regarding the permanency plan, The Family Center's lawyer assists the new caregiver with any legal challenges.

In some cases, the death of the parent signals closure of such a painful period in the experience of the family members that The Family Center's role ends shortly after the parent's funeral. In other cases, the newly configured family members seek continued support. Some caregivers who are new to their role seek training in parenting skills. Some families require grief counseling and other mental health services. As part of their adjustment to the major changes in their lives, some children may act out and get into trouble in school or with the legal system. The Family Center's continued services help to guide them toward healthy adjustment, and to secure their future in the new family structure.



Lessons Learned

Assisting parents who have life threatening illnesses to plan for their children's secure future is complicated and difficult work. While many aspects of the service have contributed to The Family Center's success, six key lessons have emerged that are central to our ability to serve families well. They are:

- recruiting the best staff members;
- providing adequate training and supervision;
- honoring the parent's decisions;
- linking clients in need to the appropriate services;
- involving our clients in every step of the planning and evaluation process; and
- ensuring service quality through research.

RECRUITING THE BEST STAFF

At The Family Center, staff are our most important asset. Staff recruitment focuses heavily on the unique skills needed for each position. Since we are a family-centered service, prospective staff members are assessed for their comfort and familiarity with complex personal issues and their ability to communicate with our clients with the respect and clarity they deserve.

Bilingual and bi-cultural competencies are high priorities in recruitment. The current staff of The Family Center reflects the cultural and ethnic diversity in New York City. Our staff is approximately one-third African American, one-third Hispanic and one-third Caucasian. Staff learn about diversity from one another as well as from those we serve.

PROVIDING ADEQUATE TRAINING AND SUPERVISION

The amount of initial and ongoing training, as well as consistent supervision, also distinguishes The Family Center's approach to service. Pre-service training prepares staff to handle their complex responsibilities. Once in the field, all employees have weekly meetings with their supervisors to review successes and issues with individual cases. Social service staff are supervised by certified social workers. All Family Center attorneys are members of The New York State Bar Association. The senior attorney has over five years experience working with families with AIDS and other illnesses. In addition to individual supervision, bi-weekly group supervision provides formal case review and analysis to develop the skills of the staff and provide rich opportunities to learn from one another. In-service training programs are held periodically to keep staff members up-to-date on new information and emerging issues in their field.

HONORING THE PARENT'S DECISION

A central principle of The Family Center is that the decisions and wishes of the parent regarding the future of his or her children are fully honored by staff. At all times, the parent is viewed as the decision-maker in regard to the children. This principle applies to a parent's decision about whether to disclose the nature and extent of her illness, to the selection of a future caregiver, and to other decisions related to permanency planning.

At times, this policy challenges some staff members, particularly when the merits of a parent's decisions are limited in the eyes of the staff member. Supervisors work closely with staff to respect the parent's decision-making autonomy while helping them to form the best possible plan. Staff are trained to assist parents in carefully assessing the strengths, weaknesses, and likely success of their plans, but there is never an attempt to dissuade a parent from a decision or particular course of action.

LINKING CLIENTS WITH SERVICES

Often, the task of developing a permanency plan highlights or is hindered by other problems within the family. For problems such as short-term mental health needs, The Family Center is prepared to provide the necessary services. In many cases, however, the client is best served to seek expertise or support elsewhere.

While referral to outside services is an element of most social service programs, it has become clear that the skill, time and attention needed to perform this task effectively can be great. Even when a staff member accompanies a parent or a child to an appointment with another provider, the transfer is not always smooth. At The Family Center, the referral process is under review to

Continued on page 12 . . .

Continued from page 11 . . .

ensure that clients have access to the best possible services.

INVOLVING CLIENTS IN ALL ASPECTS OF THE SERVICE

Working under the principle that the recipients of a service are in the best position to evaluate its value and guide its modification, The Family Center relies heavily on consumer involvement. Starting with paid family advisory boards, the Center seeks feedback and advice in planning new program initiatives, evaluating its current services, and outlining areas of improvement. Consumer input is also sought during the development and design of new programs, and the families of advisory board members are often the first to try and give feedback on new program activities. Family advisory board members also receive training in public speaking and have presented about their experiences at numerous professional conferences.

COMMITMENT TO RESEARCH AND QUALITY SERVICES

Consumer satisfaction ratings and periodic consumer input on issues related to design and delivery of services are important ways to assess and maintain the quality and accessibility of services. But these methods tell us little about our effectiveness in creating more secure futures for children through the development of viable permanency plans. Since its inception, The Family Center has had a strong commitment to rigorously assessing the strengths and weaknesses of its own service content and delivery. Program evaluation includes quarterly case reviews, detailed data base compilation of all services delivered, and longitudinal, random-

ized-control group outcome evaluation studies designed to assess the short- and long-term effects of permanency planning on child mental health and adjustment. The Family Center also conducts needs assessments in order to more fully understand the challenges facing the families it serves, and as a critical first step in designing new programs that truly meet the needs of ill parents and their children.



Conclusion

The experience of The Family Center over the last six years has demonstrated that permanency planning is a critical component of services to ill parents. Legal services are essential for any parent who wishes to create a secure plan for her child's future. Parents who are ill often need additional services, e.g., mental health counseling, substance abuse counseling, and entitlement advocacy, in order to secure plans. The Family Center's experience in providing these services suggests that coordination of legal, psycho-social and entitlements services, continuity of services before and after death, and a family-centered approach that honors the parent's decision making authority are key elements for success. At The Family Center we are committed to continuing to improve and refine our services and to teaching others what we have learned.

Barbara H. Draimin, DSW

Founding Executive Director

Jan Hudis, MPA/MPH

Founder and Research Manager

The Family Center, New York City

For more information about the Center and for free materials about our permanency planning services, please visit our web site at www.thefamilycenter.org or call Christine Pride at (212) 766-4522 ext. 28.

LESSONS LEARNED ABOUT CUSTODY PLANNING WITH HIV-AFFECTED FAMILIES

The Family Options Project was designed specifically to help HIV-infected parents make future plans for their children. Family members or friends who have taken on the care of HIV-affected children can also request services to make legal plans. Families are provided home-based social work and legal services in order to develop a plan, to secure a legal plan, and to facilitate the transition to another caregiver when a parent dies or is no longer able to care for the children. Our evaluation data and our clinical experience suggest these points to keep in mind when you are working with an infected parent or a caregiver on permanency issues.

- Be prepared to work with the family for an extended period of time. Planning is a process that can take from a few days to a few years.
- Custody planning is not a neat step-by-step process. For purposes of our program, we have identified stages in planning—outreach and education, developing a plan, securing a plan, and aftercare. We find, however, that the stages take different amounts of time for each parent and that unforeseen difficulties at any stage can send parents back to the beginning to stop the process indefinitely.
- Be prepared to help families deal with family conflict and child behavior as well as adult and child mental health issues. Some of these concerns need to be responded to before a parent can plan, or addressed concurrently with planning.
- The planning work that you do with a family is useful even if they do not make a legal plan.
- New caregivers need services to support them in their role as surrogate parents, e.g., information on how children grieve and what the children need from them, support for their own grieving, concrete information about benefits and entitlements for the children, and advice on how to handle family conflict.

Sally Mason

The Family Options Project, Chicago, IL

WHAT ARE STANDBY GUARDIAN LAWS?

During the decades of the 1980’s and ‘90s, the plight of children orphaned by the deaths of their parents from serious illnesses like HIV/AIDS became a critical social issue. Children suffered if, in addition to losing their parents, they did not know who would now care for them. Court and foster care resources were strained. Responding to that, legislators were determined to give parents legal tools to make reliable plans for their children’s futures. Section 403 of The Adoption and Safe Families Act of 1997 states:

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 consent of the parent.*

Currently 20 states have standby guardian laws. Each of these laws is unique because it has to conform to quirks in the local court system, and to the way cases have evolved locally. However, common elements exist.

HOW DOES A PARENT DESIGNATE A STANDBY GUARDIAN?

In many states, it is very simple. The name of the person chosen to be guardian is written down, and the parent’s signature is witnessed by two people—as if it were a will. That document (or a court petition that accompanies it) states that the guardianship will become active when a “triggering event” or condition occurs: usually mental incapacity, physical disability, or death. The parent need not turn the children over to the guardian at

once, but can continue caring for them as long as health holds.

ARE THE STANDBY GUARDIANSHIP DOCUMENTS APPROVED BY A JUDGE?

Yes. Ideally, they are approved before the parent becomes too sick to participate in decisions for the children. However, most states permit a court to consider a guardian designation even if the ill parent is unable to participate. If the document does not arrive at court until after the parent’s death, the designation is more like a will. While a judge will give serious consideration to the parent’s choice for a guardian, the child’s best interests — as interpreted by the judge — usually will carry even more weight.

Partnership between a social worker and lawyer can be key to successfully working with standby-guardian laws (see Hackstaff and Coelho article on p. 15 of this issue). The social worker usually is the main contact with the family, bringing parents to a realization that they need permanency planning. Lawyers typically step in later to draft the papers and present them in court.

MUST THE PARENT WHO IS CARING FOR THE CHILDREN OBTAIN CONSENT FROM THE OTHER PARENT WHO IS NOT IN THE HOUSEHOLD?

An effort must be made to locate the non-custodial parent and notify him or her of the impending guardianship action. The other parent can then either agree to the standby guardianship, or come into court and explain why it would not be in the best interests of the

children. If the objecting parent wants to take over care of the children, and there is reason to believe that he or she is not fit to do that, the issue of fitness may have to be decided by the court.

WHAT ARE THE STANDBY GUARDIAN’S DUTIES?

Of course, the guardian needs to be notified, and have an opportunity to accept or reject the responsibilities. Often the chosen guardian will be a mother or sister or best friend who is fully aware of the parent’s condition. If the designation occurs at an early point, the standby guardian will not immediately have duties; the parent will continue to care for the children. Once the “triggering event” occurs, though, the standby guardian steps in to assume as much care as the children need. Many states provide for concurrent decision-making by both guardian and parent, as long as the parent is well enough to participate. The standby guardian also may have the duty to observe when the “triggering event” occurs, gather evidence (for example, a doctor’s report on mental incapacity or physical debilitation, or a death certificate), and see that the evidence is filed in court (this may only require alerting a lawyer to file the evidence).

Keep in mind that while all of the elements of standby guardian laws discussed above apply in many states, none of them apply in all. There are so many differences between the laws that it would be impossible to describe them in this short space. Many states do not limit use of standby guardian laws to parents who are terminally or chronically ill. For example, in Illinois and Massachusetts, parents only need to show that they cannot make day-to-day decisions for the

Continued on page 14 . . .

Continued from page 13 . . .

children, whatever the cause. In California and Connecticut, elements of standby guardianship are found within a joint guardianship law: the guardian and parent begin concurrent parenting immediately, rather than waiting until the parent is too ill to care for the children. In many states, the main caretaker may designate a guardian, even if that caretaker is not a parent. In other states, the law's use is limited to parents, and both parents must agree before it goes into effect. In a number of states, a court hearing is not required if all parties consent and there are no issues in controversy. In other words, every state has its own version of a standby guardian law.

In practice, do standby guardian laws actually assure that children will have safe passage to the home of a trusted family friend or relative when their parents can no longer care for them? Yes, there is enough experience with the laws to prove their efficacy. However, they are only one legal tool among many, and may not suit every family. For example, they may not be the preferred legal strategy for a family that has two actively involved parents, or extensive material resources. Standby guardianships are especially helpful for single parent families that struggle with poverty in addition to poor health. Children from such burdened families are vulnerable to eventual abandonment and foster care. Standby guardianship can bridge them across the crisis of parental loss, into a safe, permanent home. States that have worked with standby guardian laws for some years, and that also have a large population of families at risk — like New York and Illinois — are finding that standby guardian laws can be efficiently administered in social worker-lawyer partnerships (see Hackstaff & Coelho article in this issue).

There are some interesting issues to be decided by drafters of standby guardian legislation. For example:

1. Should the law be placed in the probate code (this is the part of the law

which refers to the wills and estates of people who have died), or in the family or juvenile code? Legislators will want to decide which part of the legal code provides the most favorable environment of supportive case and statutory law to assure a good outcome for children.

2. Should the law be drafted narrowly to apply to families who are terminally or chronically ill? And if so, should physician's statements be required as evidence of this? Or would a broader law work better in your state, one that permitted more kinds of family situations to be under the standby guardian umbrella?

3. When death does occur, should there be another hearing to convert the standby guardian law to a permanent guardianship, or to consider a shift in custody to the other parent? Or should the original required search be so thorough that the guardianship automatically becomes permanent, unless challenged?

The Children's Bureau of HHS has drafted *Standby Guardian Laws: A Guide for Lawyers, Legislators, and Social Workers*. To obtain information about it, contact Pat Campiglia at the Children's Bureau, (202) 205-8060, or by e-mail pcampiglia@acf.dhhs.gov. There are very successful programs that help families use standby guardian laws and other legal tools to provide permanent future homes for children. One of these is The Family Center in New York, of which Barbara Draiman is the Executive Director, (212) 766-4522 (see article on p. 7). A law review article that describes how social worker-lawyer partnerships can work to help children in poverty-burdened, single parent families is Jeffrey Selbin & Mark Del Monte, *A Waiting Room of Their Own: The Family Care Network as a Model for Providing Gender-Specific Legal Services to Women with HIV*, 5 Duke J. of Gender L. & Policy 103 (Spring, 1998). For general information about standby guardian laws, contact Judith Larsen, Special Consultant to the American Bar Association Center on Children and the Law, foxbark@aol.com.

Judith Larsen, J.D.

PRINCIPAL LEGAL CITATIONS TO STATE STANDBY GUARDIAN LAWS

- Arkansas, Arkansas Code of 1987 Annotated, sec. 28-65-221
- California, California Probate Code, sec. 2105
- Colorado, Colorado General Assembly, HB 1375 (to go into effect 01/01/01)
- Connecticut, Connecticut General Statutes Annotated; Probate Courts and Procedures sec. 45a-624(a)-(g)
- Florida, Florida Statutes Annotated, sec. 744.304; 744.3046
- Illinois, Smith-Hurd Illinois Compiled Statutes Annotated, 5/11-5.3
- Iowa, Iowa Code Annotated, sec. 633.560 and 633.591A
- Maryland, Annotated Code of Maryland, sec. 13-901 through 13-907
- Massachusetts, Massachusetts General Laws Annotated, sec. 201-2B through 201-2G
- Minnesota, Minnesota Statutes, Chapter 257(B) [effective April 15, 2000]
- Nebraska, Nebraska Revised Statutes of 1943, sec. 30-2601, 30-2611, 30-2613, and 30-2614
- New Jersey, New Jersey Statutes Annotated, sec. 3B:12-72 through 3B:12-77
- New York, McKinney's Consolidated Laws of New York Annotated, Surrogate's Procedure Act, sec. 1726
- North Carolina, General Statutes of North Carolina, sec. 35A-1370 through 35A-1382
- Ohio, Ohio Revised Code, Commercial, sec. 1337.09(B); Probate, sec. 2111.02, 2111.042, 2111.12, 2111.121, 2111.13.
- Pennsylvania, Pennsylvania Consolidated Statutes Annotated, Title 23 Domestic Relations, Chapter 56 Standby Guardian Act, sec 23-5602, 23-5611, 23-5612, 23-5613, 23-5613, 23-5614
- Virginia, Code of Virginia, Juvenile, sec. 16.1-349 through 16.1-354
- West Virginia, West Virginia Code Annotated, sec 44A-5-1 through 44A-5-8
- Wisconsin, Wisconsin Statutes Annotated, Children's Code, sec. 48.978
- Wyoming, Wyoming Statutes (1985 & Supp 1995), Probate sec. 3-2-101, 3-2-104, 3-2-108, 3-2-201, and 3-3-301 through 3-3-305.

CHALLENGES AND OPPORTUNITIES IN THE SOCIOLEGAL RELATIONSHIP IN PERMANENCY PLANNING WITH HIV-POSITIVE PARENTS

Permanency planning is a legal service relatively new to the human service arena. Developed in the early 1990's, it provides the legal means by which parents or guardians who have terminal illnesses and who have legal responsibility for children (physical custody), can design plans for the future care of their children should they become incapacitated or die. The centerpiece of most models of permanency planning is the collaboration of professional social workers and attorneys, the complex dynamics of which serve as the focus of this article.



Permanency Planning Models

In summarizing why we engage in permanency planning, Mildred Pinott writes:

“Nothing can take away the pain of planning for another person to raise one’s children. But the law, combined with social services and counseling, can help make the process more compassionate, clear, and effective. When custody planning is in place, parents can go forward, leading their lives and loving their children, knowing that their future is assured” (Pinott, in Levine, 1996).

Models for assisting families in the permanency planning process vary significantly in their structures and funding. For instance, one model in New York City is based on a traditional family service framework, with social work and family counseling at its core, and legal service comprising just ten percent of its professional focus. Another example is a

group of private practice lawyers who focus on this service as their bread-and-butter practice, utilizing social work in more of an outside, consultative manner. The HIV Law Project has designed a legal services-oriented, yet fully integrated, model that wholly incorporates the strengths of social work intervention.

THE HIV LAW PROJECT

The HIV Law Project (HLP) is a free-standing legal services agency in New York City that began operations in 1989. The Law Project’s focus is to serve low-income, HIV-positive persons in need of direct legal services. It specializes in the areas of housing, entitlements, family, and immigration law, as well as focusing on broader, nation-wide policy and advocacy efforts. The clients represented by the Law Project have changed over the years to reflect the groups most impacted by the AIDS epidemic. Increasingly, though not exclusively, our clients are low-income people of color, with a disproportionate number of single-mothers asking for direct legal services and advocacy efforts. In response to this demand, in 1995, permanency planning was added to the agency’s scope of services, greatly changing the agency’s complexion with the addition of a social work component. The funding for this service is garnered from a combination of public and private sources, and the services are provided free to clients, who are largely on public assistance and/or Medicaid-eligible.

The integration of social work was a challenge from the start. The early incarnations of the HIV Law Project’s service model regarded the social worker as an ancillary component to the process rather than an integral part of it. A new executive director who took charge in 1999, armed with both an MSW and a JD degree, was determined to create an integrated multidisciplinary approach to the delivery of permanency planning services. Several months later, a social work supervisor was added to the existing staff of one social worker. This article draws upon the experiences of the Law Project staff to discuss how this multidisciplinary approach can be operationalized.



The Nature and Complexity of the Sociolegal Relationship

Social workers and lawyers share a great deal in their professional orientations and value bases. Both fields are founded on a commitment to human service, a respect for individual rights and autonomy, a belief in the ethic of personal empowerment, and the utility of advocacy to enhance the place of the individual in society. Both professionals are consummate problem-solvers and communicators in their own right. As Harriet L. Goldberg (1960) stated, “Among social workers and lawyers there is a high regard for the dignity and worth of people— Both professions exist to help people, and they recognize that every case differs in some respects from every other. Thus,

Continued on page 16 . . .

Continued from page 15 . . .

they share the concept of individualization and its application in daily practice.”

However, while there may be a commitment and valorous intent toward the provision of human services, social workers and lawyers are each bound by a particular set of ethical and legal rules that are sometimes at odds. Whereas social work focuses on what has been called the “best interests” model of intervention on a client’s behalf, the legal arena focuses on “pure advocacy” for an individual (Johnson & Cahn, 1995). One is a clinical approach that draws upon psychology, family theory, sociology, and organizational and motivational knowledge bases, while the other utilizes procedural interventions within a codified framework of societally evolved rules and regulations. The structural conflict between the fields is described in the following:

*“While lawyers are traditionally trained in problem solving or problem preventing on their client’s behalf, social workers, like psychiatrists and other clinicians, will initially seek to understand fully the context of the presenting problems before designing a treatment or intervention. Lawyers, certainly, can also benefit from a larger contextual perspective, and, indeed, must counsel their clients about the wide implications of the client’s decisions. Nevertheless, attorneys are clearly bound, in traditional representation, by the express wishes of their clients’ wisdom regardless of the lawyers’ assessment of the decision. Social workers, on the other hand, are trained to appreciate the client’s total circumstances and to approach every professional intervention in that light.” (Westlaw: 1-MAR Ky. Children’s Rts. J. 15, *18).*

There is some sentiment expressed that collaborative models of social workers and attorneys are not tenable. The literature is replete with references to the inherent conflicts around advocacy, client definition, privilege, confidentiality, and mandatory reporting (see for example: James, 1987; Johnson & Cahn, 1995; Barton & Byrne, 1975; Strand, 1998;

and Retkin et al., 1997). For instance, it is the lawyer’s job to serve as the individual client’s “aide de camps” in carrying forward the client’s wishes and protecting them with all legal tools available to the best of his or her ability, regardless of whether they agree with the client’s position. This is in contrast to the social work view of advocacy (James, 1987). In this construct, social workers take a more holistic approach with clients, often bringing societal concerns into the mix of interventive strategies, as well as working with the larger family system and defining the client as such.

Since the emergence of joint social work/legal programs, as in HIV work and divorce mediation, the issue of privilege has come to the fore as another potential area of conflict. The emerging body of comment on this issue clearly supports the position that social workers employed within a legal services agency are protected by the lawyer’s umbrella of privileged communication rules. New York Civil Practice Law and Rules Section 4305(a) reads: “Unless the client waives the privilege, an attorney or his employee, or any person who obtains without the knowledge of client evidence of a confidential communication made between the attorney or his employee and the client in the course of professional employment, shall not disclose, or be allowed to disclose such communication, in any action, disciplinary trial or hearing, or administrative action, proceeding or hearing conducted by or on behalf of any state, municipal or local governmental agency or by the legislature or any committee or body thereof.” For example, “such teams exist in not-for-profit law firms that represent children. Because the social worker is employed by the attorney, lawyer confidentiality rules, which are stricter than those governing social workers, apply to the social workers as well. Thus, the lawyer’s confidentiality rules may supersede the social worker’s guidelines regarding confidentiality” (Strand, 1998).

The key to resolving these inherent conflicts so that both professionals can work collaboratively toward helping the client achieve her goal can be found in a deepened understanding of each other’s roles and responsibilities, as well as untiring communication between the two fields. Additionally, Retkin, et al. (1997) suggest that “Social workers and attorneys working within the same agency should be aided by a written document which outlines for both workers and clients how these issues will be handled.” The policies and procedures of the HIV Law Project, along with a case study, illustrate how this translates into practice. Before the more technical aspects of permanency planning are discussed, however, it is essential to describe the dynamic, psychosocial concerns of the work.



The Emotional Complexities of Permanency Planning

While it can be assumed that all parents should reasonably have plans set forth for the care of their children should something untoward occur, there are many psychological factors which mitigate against such planning efforts. After all, the nature of the work of permanency planning involves confronting and managing issues of death and dying, first and foremost. And, as has been well-discussed by such writers as Kubler-Ross, those confronting life-threatening illness transverse a complicated terrain of emotional responses including denial, despair, anger, and “bargaining” for a different fate on the way to acceptance of the illness (Kubler-Ross, 1969). This set of dynamics is further complicated by the individual’s natural responses of anxiety, avoidance, procrastination, and rationalization. Therefore, it is the very sophisticated level of assessment and counseling expertise in the service of completing a concrete service function, coupled with knowledge of community-based systems for multi-problem, multi-stressed families

that is the catalyst for the legal work being accomplished successfully. Without this, clients would likely remain overwhelmed by all the stresses, unable to focus and problems solve, and trapped in their own ambivalence about dealing with the prospect of dying.

As to the partnering of law and social work in the planning process, Drainin has written of the complexities of permanency planning, “Ideally, each parent who begins to explore custody options for her children would have the help of a multidisciplinary team, including at least a mental health professional, an attorney, and an entitlement specialist, all of whom are trained in family therapy, child development, custody law, and the HIV disease process” (quoted in Taylor-Brown, et al., 1998). In this regard, it is the duty of a program to provide both the legal and psychosocial expertise to clients engaged in permanency planning. The supportive counseling and problem-solving focus by the social worker is the means by which the legal work can be successfully accomplished. In fact, insofar as an average of 30 percent of initial attempts to engage clients in the planning process fail (Taylor-Brown, et al., 1998), it is, in large part, the perseverance of the social worker in this, as well as in the working phase of the planning process, that will ensure a better chance of success.



Policies and Procedures at the HIV Law Project

It is helpful to understand the tasks and steps in the process of creating a permanency plan in the discussion of the particular policies and procedures of HLP. In describing the process below, it must be kept in mind that the policies and procedures flow from a legal services-based model and not a social work driven one. In the vast majority of instances,

the client presents to HLP with a legal issue as primary.

PERMANENCY PLANNING PROCESS

The basic steps in the permanency planning process are as follows:

- Telephone intake conducted by a legal professional to establish eligibility and the legal need(s) of the client, followed by assignment to the appropriate attorney.
- Automatic scheduling of a psychosocial assessment with a social worker if the client has minor children, to be conducted in the client’s home within one week of intake.
- At the initial meeting with the client, the social worker offers a brief description of the social work service. If agreed to, a comprehensive interview focusing on permanency planning issues is conducted. The psychosocial assessment narrative and initial care plan are developed and any other necessary forms signed.
- Case review by the multi-disciplinary permanency planning team to further clarify the plan (this may include social work referring the client to meet with the attorney at this point to counsel around legal options and their ramifications for the client).
- Follow-up contact by social work to non-parent/guardian persons who are either directly part of the plan or a part of the support network of the parent or guardian, including a home visit to the proposed standby guardian to assess their appropriateness for the designation and to assess the need for follow-up counseling, etc.
- Signing of designation (and completion of Health Care Proxy and Will if desired) with lead attorney, in the office or in client’s home.
- Completion of additional documents if a court-appointed guardianship or

other form of plan is desired.

- Continued social work contact with the client throughout the permanency plan development process to conduct an ongoing evaluation of functioning and supportive needs, and provision of short-term counseling, problem-solving, or referrals to community-based providers for other services as needed.
- Social work remains available to the client and the standby guardian over time to assist the client with such things as disclosure issues, the effects of dealing with chronic illness in the family, and any concern that may impact the permanency planning process, short or long-term.

When the above has been accomplished and no further issues remain, the legal and social work cases are closed. Clients are counseled that the office remains a resource to modify the plans in the future should their circumstances change. It is hoped that by the end of the process, the client feels confident and connected enough to return should the need arise. To further maintain connections, every 6 months the social worker phones clients who have completed plans in order to remind them that the permanency plans should be periodically re-evaluated and that the HLP remains a resource to them.

HLP’S POLICIES AND PROCEDURES

With this tenet in mind, HLP has developed a set of written policies, practices and procedures to address and minimize conflict areas, and make explicit the professional roles and responsibilities in the day-to-day operation of the team. To insure that communication is open and consistent within the team and the guidelines

Continued on page 18 . . .

Continued from page 17 . . .

explicit, the permanency planning team of legal and social work staff meets weekly to do case review of the entire docket, and to address any operational issues. The team is co-led by an attorney and the senior social worker. An additional social worker and paralegal are added to the team as increased caseload requires. The paralegal helps with the gathering of necessary documents and helps with the initial drafting of legal documents. A sampling of the policies and procedures for the more problematic issues that can arise are as follows:

- All telephone intakes are completed by either a paralegal or an attorney. This ensures that any legal areas are addressed by the properly trained professional, and it begins the client-agency relationship that includes privileged communication from the outset.
- An in-home appointment with a social worker for a psychosocial assessment is automatically scheduled at the time of intake for the client who has children in their care. (The client may, of course, refuse this appointment). This is done to transcend the client's natural resistance to planning at the outset, especially as they are usually calling for a legal concern separate from the permanency planning issue. It also enables the social worker to address any other psychosocial issues with which he or she is contending.
- A written "Statement of Understanding" is reviewed, discussed, and signed, along with the HIV release of information, at the start of the initial social work assessment home visit. This statement, offered in both English and Spanish, repeats that social work services are purely optional and can be refused. It also sets forth the reporting requirements of the social worker. While it is unclear whether such a document can fully eliminate the mandatory

reporting requirement of social workers versus the attorney/client legal privilege conflict, it is a step in the right direction toward full disclosure regarding the reporting requirement up front. As a correlate to consent and disclosure issues, a genogram, or snapshot of the client's family tree and other close intimates is drawn. This provides an opportunity both to assess the nature and quality of the client's relationships, and to broach any disclosure conflicts within the family circle of relatives and friends.

- The aforementioned weekly case review is held to ensure open communication and problem-solving. In addition, senior legal and social work staff are available on-call at any time should a potentially emergent or potentially conflicted client circumstance arise, and any such circumstance is conferenced by staff at all levels, including the executive director.
- Social work and legal staff maintain separate charts, and neither professional reads the contents of the other. The shared documents are limited to: the HIV release, the Statement of Understanding, the Family Unit Intake, the medical verification of HIV status, the genogram, and any pertinent correspondence.
- There sometimes emerges a decision point for the client regarding which type of plan best suits their particular situation. If the decision involves consideration of a written-only format vs. one that involves the court, the social worker's role is to refer the client for legal counsel before proceeding with the psychosocial counseling process. This keeps the professional boundaries clear, and ensures that the client is given appropriate legal advice.

As in most human service enterprises, the theory is often much tidier than the practice. This holds true with permanency planning. Even with clear

policies and procedures, the outline of tasks required to complete the process procedurally as described above, does not describe the complexities of completing the process. Client's fragile health status, diagnosis-related stigma, ambivalence, family dynamics, depression and anxiety, and other psychosocial issues countervene to make it a much more complicated process. As a result, plans can take anywhere from one month to over a year to complete, with many never reaching completion. The following case illustrates how the HLP social worker and attorney work together to help a family through the permanency planning process.



Ms. G

Kimberly G came to our office originally with housing and benefits problems. Due to a public assistance miscalculation, Ms. G and her two-year old child were at risk of eviction. While these matters were being addressed, Ms. G was referred to our permanency planning team. Her husband, and the father of her child, was in custody at Riker's Island Correctional Facility awaiting trial for armed robbery. She had been the victim of domestic violence at his hands, and was afraid of starting any proceeding that might include his involvement. She expressed her interest in pursuing permanency planning, and went over her options with the help of the social worker and the attorney. She was comfortable with executing a simple written designation naming her sister as standby guardian. This option did not require the involvement of her husband in its execution, even though she was made aware that he could contest her wishes at some point in the future.

She was terrified of her husband finding out that she was making arrangements, but wanted to ensure that her son would stay with her sister

should something happen to her. Toward this end, she decided to take the extra step of having the standby guardianship appointed by the court. The notice to the father in this circumstance is a constitutionally protected and absolute right. Overriding such a notice requirement is very difficult, but Ms. G insisted that we proceed in court and try to convince the court of the danger to Ms. G should her husband be notified. Our legal staff informed her that she could change her mind and withdraw her application should the judge not rule in her favor on the motion. But Ms. G wanted to proceed in spite of the probability that the judge would not grant such an application.

Ms. G required many visits by our social work and legal staff over the eighteen month period it took to resolve this matter. Much time was spent obtaining copies of relevant police reports and orders of protection issued against her husband. The social worker provided supportive counseling at every step to help the client to stick to her plan, as well as getting her connected to a support group, and helping with other psychosocial problems along the way. In addition, building a strong case to convince the court that her husband had no real contribution to make toward the formulation of a permanency plan for the child, and that her concern about her and her child's safety were legitimate, involved extensive documentation.

The petition that was eventually filed was very detailed and included an affidavit from Ms. G and eleven exhibits and attachments documenting the circumstances, including one written by the staff social worker. The intake judge was hesitant to grant such a motion because of the aforementioned reasons. She declined to rule on the matter and set a short adjournment date. This gave Ms. G an opportunity to weigh her options and consider the possibility of withdrawing the petition

or exploring the option of serving the petition on her husband in a limited or revised form. Meanwhile, both social work and legal staff continued providing counseling for the client, though with different but complimentary focuses.

On the subsequent return date, the judge ordered service on the incarcerated husband but with petition redacted of all of Ms. G's vital information such as her current address. Ms. G accepted this solution and decided to proceed. At the time, she expressed relief that she was continuing with the process rather than withdrawing her petition. Her husband was produced from Riker's Island on the next court date. Ms. G was apprehensive of what might occur when she met her husband in court. To everyone's surprise, after a brief whispered conversation with her at the counsel table, he consented to the standby guardianship. She was glad that she had gone forward with the petition and not withdrawn it as she had considered doing at the last court date. The matter proceeded uncontested and the petition was subsequently granted.

While this case involved an extraordinary scenario and intensity of professional services, it does exemplify the complexity of permanency planning and the nature and value of the sociolegal team working in concert over time.



Summary and Conclusion

The authors have attempted to present one model of a successful collaboration in the sociolegal arena. For populations that evidence a wide range of problems with a convergence of psychological, familial, health, social and legal issues, the marriage of these two often disparate professions can optimize outcomes. In an area where there is limited funding and resources, different models need to be developed and tested in an effort to best serve as many of our clients as possible within the reality of a limited budget

framework. It is crucial that communication between professionals of different disciplines be direct, open and efficient. The authors contend that while the pitfalls and challenges are many, the concerns are manageable, if within the team, there is a strong commitment to transcending turf strife, a great openness to exploring how the fields may dovetail with one another, and an untiring amount of energy and thoughtfulness invested in positive, open problem-solving. When successful, such collaboration can truly exceed the sum of its parts, and clients may thereby reap just rewards.

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HIV Law Project

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EFFECTIVE PRACTICES FOR EMPOWERING PARENTS WITH HIV/AIDS THROUGH PEER SUPPORT

Parents with HIV/AIDS struggle with multiple problems that interfere with their ability to provide effective continuity of care and permanency planning for their children. For any parent, developing a permanency plan is an important and psychologically difficult task. Parents must confront their own fears of death and the potential consequences of death on their children. When a parent is diagnosed with HIV/AIDS the task is daunting.



Complex Challenges of Permanency Planning

Developing a permanency plan and providing continuity of care are challenging tasks for parents with HIV/AIDS for numerous reasons. Disclosure is typically the first and foremost factor that effects permanency planning, especially if any of the children is HIV positive. If the parent has not disclosed his or her own HIV status to a potential guardian, asking that person to assume caregiving duties could raise questions that lead to disclosure of his/her diagnosis. Questions increase fears of rejection and stigmatization and feelings of guilt, sadness and anger. When any of the children is HIV positive, these issues become heightened. Disclosure of the child's status will be necessary to assure that the guardian will not reject the child and is willing and able to provide for all the needs of that child and others (see Murphy article on p. 23 of this issue).

Health status is a second factor that can effect permanency planning, primarily in terms of timing. After the initial shock of the diagnosis, parents begin to think about their death and the need to plan for their children's future. When the

parent develops symptoms and their health worsens, the urgency of permanency becomes more of a reality and a pressing need.

In permanency planning, the children's and the potential guardian's health also are a concern. Children may have health or developmental problems, aside from HIV, which parents will need to take into consideration when choosing a guardian. Further, HIV is now considered a multi-generational disease that infects and affects individuals of all ages. Within families, this disease is now known to infect three generations at one time (i.e., grandparent, parent, and child). Family members grieve over several losses and the number of potential guardians decreases for a growing number of orphaned children.

Parents' psychological adjustment to their diagnosis also affects permanency planning. Readiness for permanency planning is effected by their stage of grief (e.g., shock, anger, bargaining, sadness, acceptance (Kubler-Ross, 1969), coping strategies (e.g., avoidance, denial, isolation), and mental health (e.g., depression, anxiety). The parent that is in denial and depressed is less likely to develop a permanency plan for their child than a parent who has healthier coping skills. Parents who have accepted their illness can utilize their anxiety to develop a plan. A parent who chooses isolation to cope with overwhelming fear and sadness may have difficulty identifying potential guardians. Their isolation limits the number of potential guardians. In cases of domestic violence in the home, one parent may fear identifying their guardian of choice because the other parent may react with violence.

A parent's cognitive functioning also is important and can impact their ability

to develop a permanency plan. Cognitive functioning becomes impaired when the virus causes brain damage directly or indirectly from opportunistic infections. Parents experiencing dementia and those with premorbid intellectual impairment may not have the capacity to make good judgments for their children's future.

Other psychosocial factors that can effect permanency planning are poverty, abuse, substance abuse, and limited education and social support. Boyd-Franklin, Steiner & Boland (1995) suggested that poverty affects a woman's ability to access good prenatal care and nutrition, forces families into substandard housing, increases the risk of exposure to violence in the home and community, and limits access to educational resources.

Additionally, legal documents can be costly and, while free legal services are available in most communities, parents may not meet eligibility criteria for them. Finally, when picking potential candidates, parents need to consider factors about the guardian such as their financial stability, cultural and religious preference, parenting style, disciplining techniques, and risk for abuse and neglect.



Intervention with HIV-infected Parents

Given that approximately half of the parents who die from AIDS related illness die without a permanency plan (Michaels & Levine, 1992), interventions are strongly needed to help parents with HIV develop plans for continued care for their children. The majority of parents with HIV are single women of color. The complexities of their illness and psychosocial issues suggest that these

women need multidimensional supports and treatment modifications (Morris & Schinke, 1990). Treatment models need to be individualized to meet the specific needs of each client (Sue & Sue, 1990; Boyd-Franklin, Steiner & Boland, 1995) and their parenting role. Traditional psychotherapy or psychoeducational parenting groups have not been found to be highly effective with this population. These models are based on women as individuals, not as parents, and do not adequately address parenting issues (SAMHSA Women, Co-Occurring Disorders and Violence Study, 2000). Additionally, traditional psychotherapy is based on definitions of abnormal behavior that may not be accurate for minority populations with different cultural norms. Individual therapies also may conflict with various cultural ideals that stress the importance of familial and community unity.

Despite these deficiencies in traditional treatment models, little research has been done to assess the effectiveness of alternative permanency planning interventions for parents with HIV. Draimin, Gamble, Shire, & Hudis (1998) compared the effectiveness of two programs, Project Talk and Project Care, that provided guidance for women with HIV/AIDS in developing a permanency plan. Using cognitive behavior techniques in groups for HIV infected women and their adolescents, the goal of Project Talk was to increase coping skills and minimize the severe mental health consequences associated with the loss of a parent during adolescence. Project Care utilized case managers to provide home-based psycho-education about HIV disease and permanency planning. The authors concluded that both programs have strengths and weaknesses, and suggested that, ideally, these programs would be used in conjunction to meet the needs of the individual clients.

In addition, Faithfull (1997) stressed the importance of supportive group therapy to provide infected women with the

opportunity to talk with peers about complicated issues of disclosure. They found that peer support helps to lessen the burden of secrecy and decrease the isolation for women with HIV/AIDS.



Project SAFE: A Model Intervention Program

Given that traditional psychotherapy and psychoeducational parenting groups have not been effective in assisting HIV infected women to make custody plans for their children, in 1996 a model intervention program was jointly developed by staff from Children's Home Society of Florida, the University of Miami (Departments of Psychiatry, Pediatrics and Obstetrics and Gynecology), and Barry University (Department of Social Work). Funded through the Abandoned Infants Assistance Program, Project SAFE (Stopping Abandonment through Family Empowerment) developed new intervention strategies to meet the needs of HIV affected families.

Project SAFE utilizes a collaborative, community-based, consumer-driven, child-centered, family-focused perspective that offers a comprehensive, intensive treatment regimen with the goal of preventing the abandonment of infants and young children exposed to HIV or drugs during the perinatal period. The program provides psychosocial support and mental health interventions, developmental evaluation and intervention, vocational education, intensive case management, parenting skills, evaluation and training, family planning, and prevention of substance abuse relapse and/or HIV infection. The program uses an empowerment model that reflects current thinking about women's psychological growth and development through relationship interactions. It emphasizes women's desire for balance in interpersonal power, needs for reconnection and emotional bonding, empathy to others,

supported vulnerability, and confidence in relational skills (Harris & Williams, 1995; Jordan, 1989, 1991; Miller, 1986). Enhancing the health, mental health, and psychosocial status of the woman provides her with the skills to improve the quality of her and her family's lives and reduce the risk of fracturing her family.

Project SAFE's intensive case management services, particularly the peer counselors, have been the key to successful permanency planning. Each client is assigned to a three-person intervention team, with high staff-to-client ratios. The team consists of a team leader, a family support worker, and a peer counselor to serve as a role model and mentor and increase the client's level of trust in the system. The program is consumer-driven stressing the importance of peer services. Peers from the community who are HIV infected serve as family support workers and peer counselors. Consumers who have advanced through a phased treatment process have the option of functioning as peer counselors or family support workers upon successful completion of their intervention, providing hope for the clients. The model strongly stresses prevention measures and supportive efforts such as in-home interventions, improved nutrition, Head Start programs, housing, employment, residential treatment for addicts, services to fathers, and permanency planning. These efforts are effective in providing stability and permanency for children. Strategies for permanency planning include different guardianship structures such as standby guardianship, voluntary relinquishment, and family mediation.

Project SAFE's parent training/support group is based on the peer-counseling model to conjointly address emotional and parental stressors. The Project SAFE group addresses the bio/psycho/social issues that these parents struggle with on a daily basis. Examples of these issues include coping with HIV/AIDS diagnosis; grief and bereavement related to loss; domestic

Continued on page 22 . . .

Continued from page 21 . . .

violence; abuse or neglect history; and low self-esteem. At the same time, the support group addresses their basic parent education needs. Examples of these issues include: normal and abnormal child development, practical parenting skills (e.g., feeding, toileting, sibling rivalry, education, illness, safety, etc.), disciplining strategies, and effects of HIV and substance abuse on child development.

The Project SAFE peer counselors and family support workers encourage the parents to attend the group and are viewed by the parents as a model of appropriate behavior. Parents are offered incentives, such as food, store vouchers, transportation assistance, and attendance certificates to improve attendance. Within the group, parents are encouraged to provide each other with support, encouragement, and productive confrontation of negative behavior. Positive supportive relationships between the group members is fostered so women develop long-term support networks. This model allows the groups to incorporate the strengths of the parents' value systems that are based in familial and community beliefs, making it easier for them to translate the skills that they learn into their daily activities.



Recommendations

The process of permanency planning needs to be woven throughout all services provided to parents with HIV/AIDS. Services need to utilize individual peer support and psycho-educational support groups to empower parents to take control and improve their and their children's lives while addressing important parenting issues complicated by their HIV infection. Parents with HIV/AIDS need to learn how to address and solve the complex challenges they experience, become more effective parents, and plan for their and their children's present and future. The goal of these services is to cre-

ate a supportive and stable environment and improve the short- and long-term mental health outcomes for parents, children, and future guardians.

Intertwined in all HIV services, practitioners need to be asking permanency planning questions to empower parents and help them develop appropriate and realistic plans for their children's future. Sample questions include:

- Who has custody of the children?
- Does another parent have legal rights?
- Who should be involved in the permanency discussions?
- Who do they trust with their children
- Who do they trust to know their HIV status?
- Who will be a responsible guardian?
- When and where should permanency planning discussions occur?
- What legal documents do they need and how can they get them?
- When should they write these documents?
- When should they turn over custody?

Permanency planning has the potential to have a positive psychological impact on parents with HIV/AIDS and their children. Planning relieves parents' and children's anxieties. It gives parents and children choices in their future. It allows for a smoother transition for the children. It ensures a future for the children partially defined by their biological parent. Without a permanency plan, children experience many sudden, unexpected changes in their life at a time when they are dealing with the traumatic loss of their parent.



Conclusions

Traditional psychotherapy and psychoeducational interventions have failed to effect change in the ability of ethnically and culturally diverse parents with HIV/AIDS to provide continuity of care and permanency planning for their children. To address these families' complex and varied stresses, professionals need to

provide flexible and effective interventions that empower these parents and meet their parenting needs. Interventions should utilize peer counselors and family support workers to provide models of effective behaviors. Professionals, paraprofessionals, and peers need to support and educate parents and help them develop planning skills, effective coping strategies, and stronger community support systems in order to assist them in creating permanency plans for their children.

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DISCLOSURE: THE CHALLENGES AND BENEFITS FOR CHILDREN AFFECTED BY HIV

Since 1989, the Program for HIV-Affected Children & Families at the Yale Child Study Center has provided home-based psychotherapy and clinically informed case management to more than 400 vulnerable families affected by HIV. In addition to the pervasive effects of poverty and family disruption, children who are either infected themselves or raised by an HIV-infected parent confront the developmental tasks of childhood in a context in which separation due to illness and premature death become normative. Disclosure can represent a crucial ingredient in a treatment plan designed to foster security and resilience; yet for many families, the process of disclosure is complicated by stigma, guilt, and secrecy engendered by HIV/AIDS. Clinicians and case managers at the Yale Child Study Center have recognized that disclosure exists on a continuum, with parents conveying varying degrees of information to infected and affected children. Variability in approaches to disclosure, including denial of illness, veiled or disguised disclosure, and forthright discussion, sets the context for community based clinical interventions and planning for children who will likely be separated from their caregivers. Following a review of current findings related to disclosure, this article presents a developmentally informed conception of HIV disclosure that incorporates ongoing clinical experience and research with HIV affected families in order to highlight the ways in which disclosure fosters or inhibits the development of HIV affected and infected children. Finally, disclosure is examined as a powerful catalyst in the process of permanency planning for the children of infected parents.



Disclosure of an HIV Diagnosis

Few studies have examined parents' decisions about revealing their HIV or AIDS diagnoses to their children. Rotheram-Borus and her colleagues (1997) noted a disclosure rate of approximately 75% by HIV infected parents. In her study and others, older children were more likely to be told of a personal or parental diagnosis of HIV or AIDS. Parents also tended to disclose more information as they became more symptomatic (Armistead, Klein, Forehand, & Wierson, 1997; Ledlie, 1999). Disclosure rates alone, however, reveal little of the decision-making process that parents go through, or the psychosocial implications for infected and affected children.

Disclosure of an HIV/AIDS diagnosis represents a choice that parallels personal efforts by parents to confront their illness and its medical, psychological, and social sequelae. However, no decision as complex and emotionally charged as HIV disclosure—where parents confront the possibility of premature death—can be attributed to a sole motivation. Rather, the act of disclosure results from a series of inter-related motivations. The majority of parents inform their children of HIV/AIDS infection out of the desire to psychologically prepare them to cope with serious illness and perhaps death (Wiener, Battles, & Heilman, 1998). Recognizing the importance of this preparation, parents may wish to assert control of the disclosure process so the information is not revealed in an inappropriate way beyond the purview of their supervision.

Many parents, however, are unable to reveal an HIV diagnosis to an affected or infected child. As Nagler, Adnopo, and Forsyth (1995) observed, children “represent parents’ replacements and hope for immortality,” yet these aspirations become untenable in the face of HIV and AIDS. Parents may be overcome by guilt and beset by self-recrimination at having transmitted the virus to their offspring. Disclosure then requires recognition of personal responsibility and acknowledgement of negatively sanctioned behaviors related to substance abuse or sexual activity (Lipson, 1993, 1994). Unable to tolerate their own remorse and psychological pain, parents may withdraw and deny an illness that is evident to their children and loved ones. Other parents, who equate disclosure with harming their children, attempt to protect children from painful knowledge in a naïve effort to preserve the mystique of childhood innocence. Lipson (1993) suggested that the conscious fear that children cannot understand the ramifications of HIV masks a deeper fear that children will indeed grasp its fatal implications. Beyond ambivalence about psychological reactions and distress, parents recognize the stigma and social ostracism that accompany a diagnosis of HIV. Fears of rejection by family and peers are all too often borne out in a society that continues to marginalize those with HIV due to its associations with methods of infection. When secrecy overcomes reason and openness, parents live in an uneasy tension where life becomes limited by the burdens and constraints of secrecy (Gewirtz & Gossart-Walker, 2000; Reeve & Kline, 1995).

Continued on page 24 . . .

Continued from page 23 . . .



Psychosocial Implications of Disclosure for Children

Even parents who report positive disclosure experiences describe a period of fear and doubt about negative emotional reactions and even rejection once HIV becomes known. At the same time, studies of HIV affected children suggest that disclosure leads to diminished parental depression and improved family functioning (Lipson, 1993; Reeve & Kline, 1995). Results from the same studies indicate equivocal results in terms of children's psychological functioning. While disclosure of other life-threatening illnesses, such as cancer, appears to alleviate anxiety (Lipson, 1993; Reeve & Kline, 1995), HIV carries a greater burden of social stigma and isolation. Some reports indicate that children experience heightened levels of distress immediately following disclosure (Lipson, 1993; Reeve & Kline, 1995). Symptomatology may abate, however, as children are afforded continued opportunities for discussion and expression with family members, mental health and pediatric providers.

A substantial proportion of HIV-infected and affected children contend not only with their diagnosis or their parents' diagnosis, but also with myriad other stressors related to family dysfunction, parental illness, and psychosocial adversity. Once these factors are accounted for, disclosure of an HIV diagnosis does not appear to result in further decrements in children's emotional or social functioning. For many, disclosure alleviates the burden of unspoken fears and becomes a basis for further integration of painful knowledge and a foundation for permanency planning efforts.

Clinicians and Family Support Workers at the Yale Child Study Center have adopted an approach to disclosure and permanency planning that integrates empirically derived knowledge of the

effects of HIV on children's psychological functioning with knowledge of normative childhood development (see Adnopoz, 2000; Gewirtz & Gossart-Walker, 2000; Nagler et al., 1995). Any explanation of an HIV/AIDS diagnosis should include recognition of the varying developmental capacities of all involved children if it is to result in enhanced knowledge and understanding that may benefit the child (Schonfeld, 2000). Younger children rarely understand the etiology of HIV infection, or other medical conditions. A preschool child may view parental illness as an external punishment or the result of some unrelated action on his or her part (Lipson, 1994). As the same child enters the elementary school years, he or she may gradually come to understand HIV as a product of behavior. The child may recognize an association with certain high-risk behaviors, including drugs or sexual activity, yet reasoning skills are rarely sufficient to understand the complexity of viral infection. Only with further cognitive maturation and the capacity for abstract thinking can children understand the concept of a disease, how it is contracted, and how it is manifested (Lipson, 1994). In addition to constraints imposed by cognitive maturity, understanding of HIV disease remains entwined with emotional issues related to social stigma, secrecy, and potential death and loss. Children who learn of an HIV/AIDS diagnosis experience expected increases in emotional distress and worry, regardless of their capacity to logically understand the illness. The presence of distress neither argues for or against disclosure of an HIV diagnosis. However, for disclosure to represent a potentially beneficial experience for children, the inevitability of distress should be anticipated and addressed.

The issues of disclosure and permanency planning become still more important with the ongoing evolution of the HIV/AIDS epidemic from an acutely fatal illness to a chronic condition that

still portends a shortened lifespan. Children continue to experience the painful effects of HIV/AIDS, regardless of their specific knowledge and understanding of the illness and its course. Clinicians have come to accept the axiom that knowledge is preferable to the fantasies children may construct about their illness or their parent's illness. For some children, disclosure may dispel erroneous beliefs about personally causing the illness, but it may heighten fears and anxieties about abandonment. Although secrecy can represent a burden for children and parents alike, openness may accentuate anxiety because of the uncertain future of an individual infected with HIV (Nagler, Adnopoz, & Forsyth, 1995). Thus, disclosure should represent a process that neither begins or ends with the actual revelation of HIV infection.



Stages of Disclosure

A five-phase model of disclosure emerged through the work of Child Study Center clinicians and family support workers. This model is based on more than a decade of clinical intervention with children who are either infected or affected by HIV and AIDS (Adnopoz, 2000; Geballe, Gruendel, & Andiman, 1995), and it builds upon the work of other scholars in the field of pediatric HIV (e.g., American Academy of Pediatrics, 1999; Tasker, 1992). While the phases do not represent discrete entities, together they comprise a developmental perspective on disclosure. The phases in the disclosure process include: (1) the secrecy phase, (2) the exploratory phase, (3) the readiness phase, (4) the disclosure phase, and (5) the discussion phase.

SECRECY PHASE

Many parents resist informing their children about their HIV, especially when they first receive the diagnosis. In this "secrecy" phase, parents' inability to

reveal their diagnosis may reflect a state of psychological “shock” or disbelief at learning of their chronic and likely fatal illness. Although disclosure should not be viewed as a universal mandate, the secrecy surrounding an HIV diagnosis may produce a sense of dread in infected persons that interferes with their psychological adaptation, particularly as symptoms of the illness become increasingly apparent (Nagler et al., 1995). The stigma and shame that accompanies this illness, with its negative connotations related to sexual activity and substance abuse, further complicates parents’ decisions about revealing the illness to infected or affected children. Medical and mental health professionals may become the sole bearers of diagnostic knowledge, and parents may require repeated reassurance of the sacrosanct nature of confidentiality. Children of parents who remain in this phase often confront the outcomes of HIV and AIDS in isolation and without knowledge or understanding of the disease.

EXPLORATORY PHASE

The subsequent “exploratory” phase of disclosure heralds keen ambivalence about revealing an HIV diagnosis to children. The need to guard against revelation gradually diminishes as parents begin to consider disclosure. Contact with other affected families reduces feelings of isolation, yet parents contend with their HIV status for an average of 2½ years prior to any actual disclosure (Weiner, Battles, & Heilman, 1998). The exploratory phase is often recognized by a gradual progression from secrecy and denial of HIV to the use of euphemisms for the diagnosis. A parent may refer generically to being sick or ill, while others mention secondary illnesses associated with HIV.

READINESS PHASE

As parents move closer to revealing an HIV diagnosis, they transition toward the “readiness phase” of disclosure. They frequently turn to another trusted adult, a family member, friend, or well-known professional, to discuss feelings about revealing an HIV diagnosis to an infected or affected child. The parent will often rehearse potential disclosure scenarios in imagination or conversation with a trusted other. As they consider alternate scenarios related to the content of the disclosure, potential reactions by children, and ways of promoting their successful adaptation, disclosure becomes attainable.

DISCLOSURE PHASE

The “disclosure phase” occurs as children are told of an HIV or AIDS diagnosis. Disclosure can define, in a specific and comprehensible way, a condition that was implicitly recognized without ever being named. Menacing secrets are replaced by knowledge, and the task shifts toward coping with painful awareness (Nagler et al., 1995).

In most circumstances, parents have devoted considerable time and thought to their decision to inform a child of an HIV diagnosis. Preparation can allow the parent to consider both the timing and manner of the disclosure and provide opportunities for consultation with mental health and pediatric professionals. They can receive help in arranging for other trusted people to support their children in their varied reactions. The content of their explanation should be dictated by the children’s developmental status. Younger children may need assistance in understanding the importance of medical care, while having their worries and need for secure and consistent relationships recognized. Unfortunately, once some parents have decided to disclose an HIV diagnosis, they may do so in an abrupt and inappropriate manner.

In effect, their own anxiety about HIV and disclosure prevent a careful consideration of their children’s needs. Under these circumstances, children may be confronted with alarming news about a personal or parental illness with few opportunities to integrate or discuss the information in an ongoing manner.

DISCUSSION PHASE

Successful disclosure of an HIV or AIDS diagnosis should not be limited to a discrete revelation but should initiate an ongoing process of discussion among trusted family members and professionals. This “discussion phase” is essential for children to truly comprehend the meaning and implications of HIV disclosure. Opportunities for discussion, although painful, allow a child to gradually confront confusion and distress related to ideas about infection, guilt, responsibility, loss, and permanency in a way that need not overburden their coping abilities.



Implications for Permanency Planning

Many parents, whether or not they are confronted with HIV, approach their potential death with assumptions about their children’s future welfare. They may assume, for instance, that a relative or older sibling will take custody of younger children. Yet, without specific plans, these assumptions easily go awry. Although children who lose a parent to AIDS typically remain in the care of relatives, siblings are often separated at a time where the continuity of their relationship is crucial. In fact, siblings remain together in less than 50% of cases of parental death due to AIDS (Draimin, 1995). Thus, parental loss becomes exacerbated through separations from remaining family members. Although

Continued on page 30 . . .



GOOD BETS



Women, Drug Use, and HIV Infection

This book describes why AIDS is the fourth leading cause of death among women of childbearing age, and why AIDS disproportionately affects minority women, many of whom are poor, addicted to drugs, and/or the sexual partners of drug users. The book provides data from national studies on the lives of women especially susceptible to HIV infection, and it identifies prevention strategies that will lower the risk of infection in this high-risk population. Cost: \$19.95 (softcover); \$69.95 (hardcover).

S.J. Stevens, S. Tortu, & S.L. Coyle, 1998. 237 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582.

Email: getinfo@haworthpressinc.com
<http://www.haworthpressinc.com>

Effects of Substance Abuse Treatment on AIDS Risk Behaviors

Primarily written for clinicians, researchers, and policy makers, this book provides insight into how to help drug abusers avoid contracting HIV/AIDS. Specifically, the author discusses intervention methods that do not adhere to abstinence-based treatment models, and examines the dangerous effects that methadone clinics that discharge patients for cocaine use can have on the reduction of risk behaviors among heroine addicts. Cost: 19.95 (softcover); \$49.95 (hardcover).

E. Gotthell, 1998. 126 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582.

Email: getinfo@haworthpressinc.com
<http://www.haworthpressinc.com>

AIDS and Mental Health Practice: Clinical and Policy Issues

Addressing contemporary issues faced by individuals with HIV/AIDS, this informative book provides psychologists, psychiatrists, social workers, and counselors with research

and case studies that offer models for effective clinical practice at this stage of the epidemic. Each chapter is written by experts in the field and demonstrates ways to provide better services to different populations, many of whom are ignored in AIDS and mental health literature. Cost: \$19.95 (softcover); \$49.95 (hardcover).

M. Shernoff, 1999, 381 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582. Email: getinfo@haworthpressinc.com. <http://www.haworthpressinc.com>.

HIV Affected and Vulnerable Youth: Prevention Issues and Approaches

This important book will help practitioners address the needs of HIV-affected children or families with humanity, sensitivity, and ethnically sensitive interventions. Social workers, case managers, psychologists, and nurses who work with HIV-affected and vulnerable youth and their families will find unique recommendations on how to assist these individuals in resisting risky behaviors. This book also provides ways to successfully help adolescents deal with the challenges inherent to HIV, economic hardships, and substance abuse. Cost: 19.95 (softcover); \$49.95 (hardcover).

S. Taylor-Brown, 1999. 147 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582.

Email: getinfo@haworthpressinc.com
<http://www.haworthpressinc.com>

How to Conduct a Workshop for the Bereaved: A Leader's Manual

This manual provides practicing clinicians with easy-to-follow, adaptable and explicit guidelines on conducting workshops for the bereaved. Several interventions and techniques that are helpful in supporting diverse individuals and groups are presented. Cost: \$6.95.

R. Temes, 1999. 54 pages. Available from Learning Publications, Inc., P.O. Box 1338, Dept. DC95, Holmes Beach, FL 34218-1338. (800) 222-1525, Ext. DC95; Fax (941) 778-6818. www.bhip.info.net/~lpi.

Genograms: Assessment and Intervention, 2nd Edition

Using famous families as case studies, this book explains how to draw, interpret, and apply the genogram, a graphic way of organizing information gathered during a family assessment. Replete with genograms (now computer-generatable), three therapists explain how to interview for and format this tool to map family patterns, and how to use it in interpreting the family structures of 32 notables from Freud to President Clinton. This new edition highlights new developments in genogram use. Cost: \$15.30 (Genogram maker software available for \$101.50).

M. McGoldrick, R. Gerson, & S. Shellenberger, 1999. 224 pages. Available from Norton Professional Books, 500 Fifth Avenue, New York, NY 10110. 1-800-233-4830; Email: npb@wnorton.com. <http://www.npbcatalog.com>.

A Social Workers' Guide: How Laws and Lawyers Can Help you Help Seriously Ill Parents Plan Stable Futures for Their Children

This guide provides social workers with information about legal custody options and strategies for working with lawyers to develop permanency plans for children of terminally ill parents. Several case studies and useful appendices are included. Cost: Free.

J. Larson, 2000. 17 pages. Available from ABA Center for Children and the Law, 740 15th St., NW, 95h Floor, Washington, DC 20005, (202) 662-1746. Fax: (202) 662-1755. www.abanet.org/child

Standby Guardian Laws: A Guide for Legislators, Lawyers, and Child Welfare Professionals

This in-depth guide describes, compares, and analyzes the standby guardian laws in 18 states. Cost: Free.

J. Larson, 2000. 17 pages. Available from ABA Center for Children and the Law, 740 15th St., NW, 95h Floor, Washington, DC 20005, (202) 662-1746. Fax (202) 662-1755. www.abanet.org/child

AIDS: The Women's Epidemic

This publication highlights the statistics of women with AIDS, the access to care and services, and the prevention methods that should be used and why they are sometimes not used. Cost: \$4.00.

B.R. Gaverman & L.R. Wolfe, 1999. 14 pages. Center for Women Policy Studies, 1211 Connecticut Avenue, NW, Suite 312, Washington, DC 20036. (202) 872-1770; Fax (202) 296-8962. Email: cwps@centerwomenpolicy.org. www.centerwomenpolicy.org.

Building a Woman-Focused Response to HIV/AIDS: Policy Recommendations from the Metro DC Collaborative for Women with HIV/AIDS

This publication outlines the ways in which one can begin to build a woman-focused response to HIV/AIDS. The authors address the issues facing hardy reached and underserved women with HIV, focusing on incarcerated women, young women, lesbians, women living in rural communities, and immigrant women. They also address the availability of and accessibility to comprehensive woman-focused services. Cost: \$15.00 (free to women with HIV/AIDS).

B.L. Rochelle & L.R. Wolfe, 1999. 36 pages. Center for Women Policy Studies, 1211 Connecticut Avenue, NW, Suite 312, Washington, DC 20036. (202) 872-1770; Fax (202) 296-8962. Email: cwps@centerwomenpolicy.org. www.centerwomenpolicy.org.

The Metro DC Collaborative for Women Living with HIV/AIDS Telling the Story

This publication reviews the method in which the Metro DC Collaborative for Women Living with HIV/AIDS operates. It addresses the elements of the collaborative model, how to bring the community together, the qualitative research, building a network, convening meetings, developing publications,

advocacy training, and policy advocacy. Cost: \$15.00 (free to women with HIV/AIDS).

L.R. Wolfe, W. Smooth, R.A. Renterian, and B. Gaverman. 1999. 56 pages. Center for Women Policy Studies, 1211 Connecticut Avenue, NW, Suite 312, Washington, DC 20036. (202) 872-1770; Fax (202) 296-8962. Email: cwps@centerwomenpolicy.org. www.centerwomenpolicy.org.

I Never Told Anyone This Before: Managing the Initial Disclosure of Sexual Abuse Re-Collections

This book combines theory, research and practice elements that enable clinical practitioners to work in an ethical, effective manner with clients who disclose memories of sexual abuse. The author suggests ways in which practitioners remain free from legal risk amidst the "false memory" debate era. Other specific areas of discussion include: how to facilitate and manage first-time disclosure of abuse stories; therapeutic use of memories of sexual abuse; the function of memory in identity formation; and facilitation of disclosures of traumatic history. Cost: 19.95 (softcover); \$49.95 (hardcover).

J.A. Gasker, 1999. 171 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582. Email: getinfo@haworthpressinc.com. www.haworthpressinc.com.

Economic Conditions and Welfare Reform

The relationship between welfare case-loads and the economy is one of the key issues addressed in this book. Using the most current data available, a group of the nation's leading researchers examines the effects of welfare reform prior to and after enactment of the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA). Cost: \$40.00 (cloth); \$22.00 (paperback).

S.H. Danziger, Ed., 1999. 321 pages. Available from W.E. Upjohn Institute for Employment Research, 300 S. Westnedge Avenue, Kalamazoo, MI 49007-4686. (616) 343-4330; Fax: (616) 343-7310. Email: publications@we.upjohninst.org.

From Surviving to Thriving: A Therapist's Guide to Stage II Recovery for Survivors of Childhood Abuse

This book provides practitioners with step-by-step guidance for working with adult survivors. Practitioners will find self-contained,

focused, and incremental interventions as well as several clinical topics including: an overview and detailed outline of the incremental recovery process; diagnostic issues; pitfalls and positive strategies for establishing the therapeutic relationship; building a foundation for effective therapy by reframing the client's self-concept; explanations of pathological symptoms in the context of necessary and "brilliant" survival defenses; and workable, specific, and sequential interventions for each stage of healing designed to become autonomous and self-generating for the client. Cost: \$24.95 (softcover); \$49.95 (hardcover).

M. Bratton, 1999. 282 pages. Available from The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. (800) HAWORTH; Fax: (800) 895-0582. Email: getinfo@haworthpressinc.com. www.haworthpressinc.com.

The Multilingual Access Model: A Model for Outreach and Services in Non-English Speaking Communities—Asian Women's Shelter, San Francisco, CA

This workbook provides an excellent resource for agencies that wish to meet the unique needs of women in non-English speaking communities who are directly affected by domestic violence. The workbook details one agency's efforts in meeting the needs of a diverse community of women who have experienced domestic violence, and describes the Multilingual Access Model (MLAM) as a tool for practitioners and advocates to communicate with non-English speaking women who are physically abused in their personal relationships. Cost: Free.

B. Masaki, M. Kim, & C. Chung, 1999. 24 pages, plus attachments. Available from: The National Resource Center on Domestic Violence, 6400 Flank Drive, Suite 1300, Harrisburg, PA 17112. (800) 537-2238; Fax (717) 545-9456.

It Can Happen to You: A Video about Teen Pregnancy and AIDS

This unique documentary was produced and directed by a diverse group of teenage youth. Targeted at teenage youth, the video focuses on prevention of behaviors and activities associated with risk for pregnancy and AIDS. It contains moving interviews with teen parents and people with HIV and AIDS. Cost: \$89.95.

1995. 17 minutes. Produced by Project YES. Available from Injoy Videos, 1435 Yarmouth, Suite 102, Boulder, CO 80304. (303) 447-2082.

Continued on page 28 . . .

Continued from page 27 . . .



Web Resources

AIDS Alliance for Children, Youth & Families

www.aids-alliance.org
phone: 202-785-3564
email: info@aids-alliance.org

The AIDS Alliance provides education, training and support to children, youth and families affected by HIV and AIDS. They support health care and social service providers serving the HIV/AIDS community, and they participate in advocacy efforts at the federal level. They also provide an excellent news alert that is on the web site and can be e-mailed to interested individuals.

WORLD

www.womenhiv.org
phone: 510-658-6930

Women Organized to Respond to Life-threatening Diseases (WORLD) is an information, support and education organization by and for women and youth with HIV/AIDS. Services include a monthly newsletter, retreats, HIV University, support groups and a team of peer advocates. The web site, currently under construction, contains informative articles regarding women and youth HIV issues, including pregnancy, disclosure and treatment information.

National Pediatric & Family HIV Resource Center (NPHRC)

www.pedhivaid.org
phone: 800-362-0071

The National Pediatric & Family HIV Resource Center at the University of Medicine & Dentistry of New Jersey is a nonprofit organization that serves professionals who care for children, adolescents and families with HIV infection and AIDS. The web site includes scientific information, including preventing perinatal transmission, care and treatment, research, and online education. It also includes fact sheets, book and video catalogs and links. This web site is designed for care providers.

Francois Xavier Bagnoud (FXB) Center

www.fxbcenter.org
www.kidsconnect.org
phone: 973-972-0410

The FXB Center, a Pediatric HIV Care Center at the University of Medicine & Dentistry of New Jersey is an internationally

recognized model for the care of mother to child transmitted HIV disease. Their web site includes information on treating HIV, training, caring for your child (including signs & symptoms, well care, immunizations), frequently asked questions, and coping with HIV. This site is geared to parents of children with AIDS/HIV.

The FXB Center also has a web site called Kids Connect which is geared to assist children and youth with HIV/AIDS. The web site is an interactive environment in which children can learn and have fun.

National Pediatric AIDS Network (NPAN)

www.npan.org
phone: 800-646-1001
email: gary@npan.org

NPAN is a resource for information on children and adolescents with AIDS/HIV. They provide information on topics such as: services for children and adolescents, publications, educational resources and treatment. The web site includes information on clinical trials, complementary therapy, pregnancy issues, government resources, databases and statistics, legal issues and more. They have a very extensive listing of related organizations that link to other web sites.

Elizabeth Glaser Pediatric AIDS Foundation

www.pedaids.org

The Pediatric AIDS Foundation funds and conducts critical pediatric AIDS research that will lead to prevention and treatment of HIV infection in infants and children. They play a leadership role in establishing a national pediatric AIDS research agenda and promoting education awareness and compassion. Their web site includes: research, programs for education and compassion, a pediatric HIV/AIDS fact sheet, and other information on pediatric AIDS.

The Center for Women Policy

www.centerwomenpolicy.org
phone: 202-872-1770

The Center for Women Policy Studies is an independent, national multiethnic and multicultural feminist policy research and advocacy institution. The Center addresses issues that have significant implications for women. Their work incorporates the perspectives of women, in all their diversity, in the formulation of public policy that ensures the just and equitable treatment of women. Their web site includes a state legislative report, action alerts, a publications catalog, and an affiliates quarterly report.

Children with AIDS Project

www.aidskids.org
phone: 602-973-4319

Jim Jenkins, an adoptive parent of a child that was born with HIV, founded the Children with AIDS Project (CWA). CWA offers a variety of services for children infected/affected by AIDS or drug exposed infants who will require foster or adoptive families. CWA works to create adoptive, foster, family centered care programs that are both effective and compassionate. Their web site includes: links to adoption and foster care sites, an interactive bulletin board, CWA project results, and links to many AIDS related sites.

Tuesday's Child

www.tuesdayschild.org
phone: 310-204-2081
email: info@tuesdayschild.org

Tuesday's Child is committed to meeting the material and emotional needs of families where HIV infection or an AIDS diagnosis has an impact on children. They provide material assistance, financial support for burial expenses, and the monthly opportunity for informal peer support. Tuesday's Child strives to help families remain intact and gain access to all appropriate resources. Their web site includes: a list of the Tuesday's Child programs, a link on how to help, facts on children with HIV/AIDS, and an AIDS Resource List.

HIV/AIDS Information Center: The Journal of the American Medical Association

www.ama-assn.org/special/hiv
email: hiv-comments@ama-assn.org

The JAMA HIV/AIDS Information Center is designed as a resource for physicians and other health professionals. The site is produced and maintained by JAMA editors and staff under the direction of an editorial review board of leading HIV/AIDS authorities. The web site features current HIV/AIDS news, a library of resources, education and support information, a list of policies and resources, and the latest news on prevention.

Children Affected by AIDS Foundation

www.caaf4kids.org
phone: 310-258-0850

The mission of the Children Affected by AIDS Foundation is to make a positive difference in the lives of children infected with HIV and affected by AIDS in this country by helping to meet their multifaceted direct care needs, advocating and educating on their behalf, and bringing joy and fun into their lives. Their web site offers a short list of links regarding education/prevention/transmission, policy, statistics, and health/treatment.



CONFERENCE LISTINGS



9th Annual Conference on Emerging Issues in Mediation

This conference will provide a wide range of information on the latest issues, techniques and ideas in mediation. Workshops will focus on family, community, policy, and skill building. Cost: \$210 (discounts for students and WAM members)

DATE: November 1-3, 2000

LOCATION: Madison, WI

SPONSORING AGENCY: University of Wisconsin-Madison Division of Continuing Studies Professional Development and Applied Studies, and Wisconsin Association of Mediators

CONTACT: Mediation Registration, Pyle Center, Dept. 102, 702 Langdon ST., Madison, WI 53706-1487. Ph: (800) 442-4617 or (608) 262-7942; Fax: (800) 741-7416 or (608) 265-3163.

Connecting Generations—Strengthening Communities

This national conference will explore how generations can work together to promote social change. Cost: \$225 (discounts for students and seniors)

DATE: November 10-11, 2000

LOCATION: Philadelphia, PA

SPONSORING AGENCY: Temple University Center for Intergenerational Learning

CONTACT: Temple University Center for Intergenerational Learning, 1601 N Broad Street, USB 206, Philadelphia, PA 19122. Ph: (215) 204-6970; Fax: (215) 204-6733; www.temple.edu/cil.

Visions for Families: Continuity and Change Across Cohorts and Generations

The national NCFR conference provides a forum for family professionals to network and disseminate the latest research and policy information in the diverse fields of the family.

DATE: November 10-13, 2000

LOCATION: Minneapolis, MN

SPONSORING AGENCY: National Council on Family Relations (NCFR)

CONTACT: NCFR, 3989 Central Avenue NE, Suite 550, Minneapolis, MN 55421. Ph: (888) 781-9331; Fax: (763) 781-9348; E-mail: ncfcr3989@ncfr.org; www.ncfr.org

NAFBS 14th Annual Empowering Families Conference

The theme of this national conference is “Kicking it up a Notch: Harmonizing with Families.” It will provide an opportunity for professionals and community members to gather new ideas and share thoughts about promoting the well-being of families. Cost: \$245-370.

DATE: November 29-December 2, 2000

LOCATION: New Orleans, LA

SPONSORING AGENCY: National Association for Family-Based Services (NAFBS)

CONTACT: NAFBS Conference Coordinator, NAFBS, 100 Oakdale Campus, W310, The University of Iowa, Iowa City, IA 52242-5000. Ph: (319) 335-4141; Fax: (319) 335-4039; Email: jo-dickens@uiowa.edu; www.nafbs.org

Zero to Three’s 15th National Training Institute

This conference will include internationally recognized faculty; plenaries on timely topics in policy, research and practice; an in-depth symposia; concurrent peer-reviewed field presentations; peer-reviewed posters; optional full-day pre-institute forums, post-institute intensive dialogue sessions; and state-of-the-art publications and videos. Cost: \$395.

DATE: December 1-3, 2000

LOCATION: Washington, DC

SPONSORING AGENCY: ZERO TO THREE

CONTACT: ZERO TO THREE, National Center for Infants, Toddlers and Families, 734 15th Street, NW, Suite 1000. Ph: (888) 733-5364. www.zerotothree.org.

15th Annual San Diego Conference on Responding to Maltreatment

This conference will increase professional skills in prevention, recognition, assessment, treatment, and investigation of all forms of child maltreatment, including those related to family violence and substance abuse. Cost: \$415 through 12/15/00; \$455 after 12/15/00 (group and student discounts available).

DATE: January 22-26, 2001

LOCATION: San Diego, CA

SPONSORING AGENCY: Center for Child Protection, Children’s Hospital San Diego

CONTACT: Registration Coordinator, Center for Child Protection, Children’s Hospital San Diego, 3020 Children’s Way, MC 5017, San Diego, CA 92123-4282. Ph: (858) 495-4940; Fax: (858) 974-8018; E-mail: mholmes@chsd.org.

The 13th National Conference on Child Abuse and Neglect

This conference deals with the prevention of child abuse and neglect on a national level. Conference attendees are expected to include more than 2000 practitioners and researchers from the fields of social work, child welfare, education, mental health and law enforcement, as well as child advocates, corporate leaders, parents, volunteers, and others. Cost: \$275.

DATE: April 23-28, 2001

LOCATION: Albuquerque, NM

SPONSORING AGENCY: The Office of Child Abuse and Neglect, within the U.S.

Department of Health and Human Services, Administration on Children, Youth and Families, Children’s Bureau

CONTACT: PaL-Tech, Inc. 1901 North Moore Street, Suite 204, Arlington, VA 22209. Ph: (703) 528-0435; Fax: (703) 528-7957; Email: 13Conf@pal-tech.com.

Continued on page 30 . . .

Continued from page 29 . . .

**“Health for All in 2010: Confirming Our Commitment — Taking Action”:
The Fifth Annual Conference of
Community-Campus Partnerships
for Health**

January 2000 marked the launch of the Healthy People 2010 Objectives for the Nation, which set the nation’s public health goals for the next decade: to increase quality and years of healthy life; and to eliminate health disparities that are associated with race, ethnicity and socioeconomic status. This 5th anniversary conference seeks to demonstrate the contribution that community-campus partnerships can make to promote health, reduce health disparities, and improve quality of life. Cost: To be announced.

DATE: May 5-8, 2001

LOCATION: San Antonio, TX

SPONSORING AGENCY: Community-Campus Partnerships for Health

CONTACT: CCPH. Ph: (415) 476-7081; Email: ccph@itsa.ucsf.edu; <http://futurehealth.ucsf.edu/ccph.html>.

**Voices 2001: The National
Conference on HIV/AIDS and
Children, Youth & Families.**

This conference will include pre-conference forums and institutes, special events, workshops, plenary sessions, and an advocacy day on Capitol Hill. Participants will include people living with and affected by HIV/AIDS, health care and social service providers, mental health professionals, peer educators, program administrators, researchers, and advocates. Cost: \$280 for AIDS Alliance members; \$375 non-members.

DATE: May 5-8, 2001

LOCATION: Washington, DC

SPONSORING AGENCY: AIDS Alliance for Children, Youth & Families

CONTACT: AIDS Alliance for Children, Youth & Families, 1600 K Street, NW, Suite 300, Washington, DC 20006. Ph: (202) 785-3564; Fax: (202) 785-3579; Email: info@aids-alliance.org.

Continued from page 25 . . .

not a prerequisite for permanency planning, disclosure may serve as a catalyst for the planning process. That is, the openness and, sometimes, relief that follows disclosure may allow a parent to more thoroughly consider potential permanency plans that will sustain sibling and family relationships. Plans are not sufficient, however, without legal arrangements.

In a study of 151 HIV infected parents and their 171 adolescent children (Rotheram-Borus, Draimin, Reid, & Murphy, 1997), for instance, almost three-quarters of the teens had been told of their parent’s HIV diagnosis, and most of the parents had developed formal or informal permanency plans for their children. Virtually all of the parents who made a permanency plan consulted the potential guardian, and almost all of the plans were agreed to by the chosen guardian. Among both the disclosing and non-disclosing parents, however, legal custody arrangements were rare, occurring in less than one-quarter of cases with some form of permanency arrangement. The high rates of permanency planning and their communication to affected children are encouraging, as they indicate that many parents are able to address their children’s needs in a playful and thoughtful manner. The relative lack of legally sanctioned custody arrangements, however, raises greater concern. During a period of grief, arrangements based on verbal agreements may be jeopardized. Therefore, while disclosure can help to facilitate the permanency planning process, legal guidance and mechanisms are needed to ensure the continuity of caregiving relationships for children. Additionally, comprehensive support services are needed to help all the family members work through their reactions to the disclosure and the impending and actual loss that they face.

Robert A. Murphy, Ph.D.

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